

**The Colonial Dynamics of Health Care:  
An Ethnographic Study in  
Vancouver's Downtown Eastside**

by  
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## Ethics Statement

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

- a. human research ethics approval from the Simon Fraser University Office of Research Ethics

or

- b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University

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## **Abstract**

This study examines how colonialism continues to be enacted in encounters between health care providers and people ('residents') who live with HIV and use illicit drugs in Vancouver's Downtown Eastside, Canada. I extend critiques of colonialism to analyse the health care experiences of Indigenous and settler residents, based on two years of participant observation and interviews at a medical clinic and drop-in centre, in an organization known as Vancouver Native Health Society. I contend that colonialism continues to be enacted through multiple interacting hierarchies of power which accentuate the knowledge, agency and contributions of providers and the vulnerability, disorder and needs of residents. With particular attention to the political economy and moral dimensions of care, I conceptualize these hierarchies of power as 'colonial dynamics'. The heightened importance of professional boundaries in this setting, I argue, is a response to the risks that relationships with residents were seen to present, and that elisions in conceptualizing these boundaries often caused providers to be unaware of harms they enacted in the delivery of care. Residents negotiated the asymmetries of power by engaging in covert strategies I refer to as 'health work'. I argue that the negative impacts of colonial dynamics, combined with residents' ongoing exposure to inequities and the broader regulation of their lives, could harm their sense of themselves as persons. I conceptualize this as moral violence. I suggest that the colonial dynamics of health care can also negatively impact providers by subordinating their personhood to the temporal and functional aspects of their roles and by exaggerating their responsibilities for residents' lives and behaviors. I argue that the power of personhood in supportive relationships with providers temporarily mediates residents' experiences of the asymmetries of power in health care and constitutes relational medicine which, for many, is important to their experiences and the efficacy of care.

**Keywords:** colonialism; inequities; health care relationships; professional boundaries; addiction; personhood

In loving memory of Anna 'Cookie' Menow and Orien 'Steven' Toulouse.

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# Chapter 1. Introduction

Vancouver's Downtown Eastside (DTES) may be among the most studied blocks on the planet. The area captured international attention in 1997 when health researchers found it had the highest rates of HIV in the developed world (Munro, 1997). Images of the area's dank alleys, emaciated residents injecting drugs, and open drug market have circulated widely. Since 1997, funding for HIV and addiction treatments from public and private sources, nationally and internationally, has poured into the area for research and services that aim to improve the health of people living in the DTES. The area, Culhane (2011) writes, 'is one of those spaces in which the global pharmaceutical corporations have organized a "guinea pig economy" based on research with human subjects' (p. 259). The area has become a lightning rod for national debates about harm reduction, supervised injection sites, and, since 2016, strategies to curb the dramatic spike in deaths from fentanyl.<sup>1</sup> Other factors that have impacted local realities include the City of Vancouver's efforts to assert itself as a world city by hosting events such as the 2010 Winter Olympics, the demand for urban real estate which has accelerated gentrification, and neoliberal reforms of health and social programs (Blomley, 2004; Sommers, 2001). Yet, despite the flourishing health research and service industries, little is known about residents' understandings of health, their experiences of health care, and the practices that help or hinder their feelings of well-being.

In this study, I use the terms 'resident' and 'provider' to differentiate the two main groups of participants according to their position within the structured asymmetries of health care encounters. The people I identify as residents lived with HIV, regularly used street drugs, participated in street life, and relied on a range of institutional services and supports such as health care. Most residents resided within the DTES. The people I define as providers were those being paid to deliver health services, who were not engaged in street life nor dependent on local services. Most providers lived outside the area and commuted in for work. This group included administrators, outreach workers, counsellors, nurses, physicians, social workers, Indigenous Elders who led or

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<sup>1</sup> In 2015 overdose deaths began rising precipitously due to the illicit use of fentanyl or other drugs laced with fentanyl. The 1998 record of 400 drug overdose deaths in BC was surpassed for the first time in 2015, reaching 518, then climbing to 993 in 2016, and then to 1422 in 2017 (Ministry of Public Safety and Solicitor General, 31 Jan 2018).

participated in programs, medical office assistants, intake workers and pharmacists. Occasionally I refer to their specific roles or titles, such as physician, intake worker, or clinic manager to highlight differences in their relative status and influence. Both participant categories are problematic. Many people living in the DTES do not share any of the characteristics that define residents in this study. As I elaborate further in Chapter 3, 'resident' and 'provider' fail to account for the messiness and fluidity in these categories. Some positions, attributes and social relationships confound these categories and the assumptions of difference that are implicit with them. However, alternative terms reinforced social and institutional hierarchies, confused my reference to each group, or were offensive to residents.<sup>2</sup> To counter the depersonalizing nature of my participant categories, throughout the dissertation when using a longer excerpt from field-data or when I discuss these in more detail, I assign each party a fictitious name.

How has the intensive focus on residents' health influenced their well-being? Residents now have ready access to sterile needles for injection drugs, supervised injection sites, medical care and social services. Death from HIV infection is now infrequent as most of the residents living with HIV take antiretroviral drugs (ARVs). Overall, however, statistics show that residents in the DTES still have poorer health and die younger than people living outside the area. For example, the mortality rate for female injection drug users (IDUs) in the DTES was almost 50 times higher than for women in the province overall (Spittal, 2006). And the overall life expectancy rate for residents from 2005–2009 was 78.0 years compared to 82.6 years for people living in other parts of Vancouver (City of Vancouver, 2012). As elsewhere in Canada, Indigenous peoples are 'disproportionately located in the poorest neighbourhoods . . . [and] at the bottom of the socioeconomic hierarchy' (Culhane, 2003/04, p. 596). In the DTES, where approximately 10% of residents are Indigenous in contrast to 2% in

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<sup>2</sup> 'Addict', 'marginalized', or 'vulnerable' defined residents by their use of drugs and/or reflected the standpoint of providers. Importantly, all of these terms were offensive to residents. Terms such as 'participant', 'informant' and 'collaborator' confused both groups of participants involved in the study, as both providers and residents participated. I rejected acronyms, like PLWH for 'person living with HIV', because it prioritized the medical category of HIV. 'Client' and 'patient' invoked the hierarchies of institutional relationships and erased the personhood of residents. Although it is less appropriate as a general referent, I sometimes use the word 'patient' in the context of medical care to connote the de-emphasis on personhood and the scripted roles in clinical settings.

Vancouver overall (City of Vancouver, 2013)<sup>3</sup>, the incidence of HIV infection among injection drug users is twice as high among Aboriginal residents than non-Aboriginal users (Craib et al., 2003).

The terms used to identify people of Indigenous and non-Indigenous ancestries are contentious and elaborated later in this chapter. In brief, I use the term 'Aboriginal' when referring to health polices, research and programs, and providers' practices. My use of Aboriginality in these contexts indexes the prevailing – colonial – beliefs in health care about Indigenous' Peoples' need for professional intervention and governance. I use the term 'Indigenous' to reflect the social, cultural and linguistic diversity of Indigenous Nations in Canada and of Indigenous people in the DTES. I use the term 'settler' for those who do not have Indigenous ancestry.

I conducted fieldwork in the area from May 2009 to April 2011 and observed inequities between the health of providers and the residents who participated in this study. Despite efforts to stay in touch, I have lost contact with many participants since fieldwork ended, but the reasons I lost contact with each group are not the same. Of the 49 providers who participated in my study, two providers passed away but the loss of contact with remaining providers can be attributed to their retirement or relocation. While I may have lost contact with some residents due to incarceration or relocation, most of the residents I lost contact with died from various causes, such as AIDS-related illnesses, cancer, liver disease, suicide, and suspected overdoses. Of the 50 residents who participated in interviews, 15 have since passed away.

Although the role of poverty as a determinant of ill health is recognized by health officials, researchers and providers, the social and material disadvantages of residents' lives continue to worsen. After taxes, 53% of residents are low-income compared to 21% in Vancouver at large (City of Vancouver, 2013). Meanwhile, welfare subsidies shrink further each year, making it harder to make ends meet given the spiraling cost of living in the country's most expensive city (Brown, 21 June, 2017). During fieldwork, the maximum total monthly welfare assistance for a single adult under age 65 (with shelter allowance) was \$657.92, while the average rent for a one-bedroom apartment in

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<sup>3</sup> Using Statistics Canada data, Patrick Brethour (13 February 2009) reported that 14% of residents in the DTES were Indigenous compared to 2% in Vancouver overall.

Vancouver was approximately \$900.<sup>4</sup> Many residents involved in this study had disability benefits which, with an additional nutrition allowance, could increase welfare subsidies to a *maximum* of \$1111.41 per month. As of October 16, 2017, welfare rates remain unchanged, while rents continue to skyrocket: one news article reported that the *average* cost of rent for a one-bedroom apartment in Vancouver had risen to \$2120 (Ip, 16 October, 2017).<sup>5</sup>

My interest in exploring how residents' histories and realities influenced their experience of health care was informed, in part, by my experiences as the daughter of a Czech immigrant and my experiences as a nurse. Observing my father's unease and social restraint among Canadians, in contrast to his relaxed, animated manner among fellow Czechs, I began thinking about the 'two-worlds' of his identity and relationships. Canadians who interacted with my father often commented on his thick accent and sometimes acknowledged his musical talents but rarely saw his 'old country' world with its sources of vitality, his strong connections to place and his courageous escape from communist rule – all central to his identity, values and life in Canada.

My first job as a nurse in a small hospital adjacent to a First Nation reserve introduced me to another kind of 'two worlds', this time created by colonization. I recall being frustrated at work one night when a young family arrived at the emergency entrance with a minor medical concern. I did not see, until the physician later explained, how overcrowded living conditions on the reserve sometimes left people with no alternatives for support. The frustration of that incident, I later saw, thrived on the limits in my nursing education which did not include any content on colonization, health inequities and Indigenous Peoples and on the anxiety I felt as a new nurse whose knowledge and skills were often inadequate to fulfill my responsibilities. Outside work, however, I was struck seeing how Indigenous culture 'lived' as families assumed long-established roles around the annual eulachon runs or assembled for feasts. In the years of nursing work that followed, the influence of these formative experiences turned my attention to the persistent gaps between providers' care and patients' social realities and

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<sup>4</sup> Based on Canadian Mortgage and Housing data, for 2012 the average rent for a one-bedroom in Vancouver was \$1,045, and the average rent for an SRO was \$416 (City of Vancouver, 2012).

<sup>5</sup> Although more residents are being displaced to outlying areas as pressure for urban real estate intensifies, health and social services for those in abject poverty living in the lower mainland of British Columbia remain concentrated in the DTES.

experiences, and between the health status of Indigenous Peoples and settlers which public health and other health services seemed unable to address. Having taken courses in anthropology, I was confident that its methods and theories would offer different insights into the relationship between colonialism, inequities and how these influenced patients' experiences of health. HIV, with the social dimensions of its transmission and disproportionate spread among the poor and socially marginalized, presented an ideal portal to explore the connections between these areas. With that, I temporarily exited nursing to commence a PhD in anthropology.

I had taken the bus through the DTES many times while living in the suburbs of Vancouver but never spent any time there until my doctoral studies. My introduction to the DTES came through my involvement with an ethnographic project, *Stories and Plays*, led by my supervisor, Dr. Dara Culhane (2011), in Spring 2008. The project took place within the space of the Positive Outlook Program, a drop-in centre for people living with HIV, run by Vancouver Native Health Society – or 'Native Health' as it's more commonly known. Following the study, I began volunteering with a weekly women's group at the Drop-in Centre. On the basis of her favourable experiences with other anthropologists, the coordinator invited me to conduct my PhD research there. The DTES was well suited as a field site given the area's poverty, the local HIV epidemic and its higher proportion of Indigenous people.

The coordinator introduced me to the coordinator of the associated medical clinic, a physician, who told me that providers in the Clinic were experiencing 'research fatigue' from their involvement in studies led by external researchers. However, he needed someone to complete an evaluation of an in-house, *Patient Self-Care Management Study* that involved providers and residents in the Clinic and the Drop-in Centre. This randomized controlled study examined the impact of health-coaching sessions on residents' understandings of HIV, their use of anti-retroviral drugs (ARVs) and their emotional well-being (Tu et al, 2013). On agreeing to perform the evaluation in exchange for access to the Clinic for my PhD research, the executive director signed a Letter of Agreement (Appendix A) and confirmed Native Health as my field site.

## 1.1. Purpose and research questions

*We all live in two worlds. You have to deal with it ... I live down here and have to struggle and survive down here on my own, to be who I am, who I know I'm capable of. (Resident Int. April 17, 2011)*

The overall aim of my study was to understand how colonialism continues to be enacted in health care encounters by examining how the histories and 'world' of residents who use drugs and live with HIV interacted with the 'world' of health care. In preparatory reading for the study, I had noted how 'the poor' of North America and 'the poor' nations of less industrial countries were portrayed in health literature about HIV and the uptake of ARVs. What role, I wondered, did the histories of colonialism play in this? My initial plan was to conduct a comparative study between the DTES and a country in sub-Saharan Africa to explore how histories of colonialism influenced the translation of scientific facts about HIV in provider-patient relationships in two geographically distant settings. I was unable to secure a second site in the required timeframe, but this early conceptualization took me to fieldwork in the DTES with several questions: How did residents' backgrounds and social realities influence how they understood HIV and experienced and responded to providers' practices? How did the epistemologies, structures and discourses of health care influence providers' beliefs about residents and how they interpreted and responded to residents' concerns? How were providers' and residents' understandings, beliefs, practices, and experiences shaped by colonialism? Where did residents' and providers' understandings, beliefs, expectations and priorities differ, align or collide?

Over the course of fieldwork, I realized that I also needed to consider the moralities and temporalities of care. I became more aware of how colonialism was enacted in my own thinking and relationships with residents, while also realizing that the colonial context of health care encounters didn't preclude strong, supportive relationships that were significant to residents and providers alike. What contributed to this? During fieldwork several additional questions emerged. What practices did residents and providers use to engage, maintain, or limit interactions? What factors facilitated or constrained each party's openness in responding to the other? How did providers and residents understand, experience and navigate the complicated contexts of health care when accessing, delivering or receiving care? When and where did providers and residents perceive the influence of colonialism, how did they understand it,

and how did those understandings match or challenge my own? How did my awareness and understanding of colonialism shift and change over the study? What was it about relationships with residents that often compelled and impacted providers and also myself so personally and what did this reflect about the colonial dimensions of health care relationships?

## **1.2. Vancouver Native Health Society**

Vancouver Native Health Society, which I subsequently refer to by its local name, 'Native Health', was the main institutional site and contact point for me to engage and communicate with residents throughout the study and has remained so in the years since fieldwork ended. For the Indigenous executive director, Lou Demerais, the Nativeness of Native Health resided in a way of being that recognized the interconnectedness of all life and valued respect, acceptance and making residents feel welcome. He explained:

We offer more of a comfort zone. . . . We try not to be judgemental in any way and emphasize that with our staff. You know, we're not just here to provide a service, . . . we want to make things as best as we can make them [for residents]. That means meeting with the people, where people actually are and trying not to say, 'we have the answers for you', . . . [but] how can we be of help to you? (Lou Demerais, Interview, 22 October 2009).

An Indigenous provider told me that from the beginning, Native Health was a friendly place and attributed this to the fact it had been set up by people who'd 'been there' (Field Notes, 19 August 2009). I have held many jobs as a nurse but have never witnessed a health care setting with so much goodwill, affection and humor between providers and patients, nor such a widely shared commitment among providers to serving patients. It was evident in providers' readiness to go beyond the conventional parameters of their roles, their efforts to remain flexible despite the structures of care and in the personal (and personalized) acknowledgements of residents' preferences. It would have been easy to observe colonial dynamics in another setting, but it is precisely the atmosphere and caliber of providers at Native Health that made it an excellent site to for this study. Many providers outside the organization shared my view, and many residents, despite the complexities examined in this dissertation, also made comments

that, like the following, attested to how the organization's vision lived at the interface of care:

[Providers at the other places down here say] 'what do you need, what do you want, this is what we'll do for you but you gotta follow this, you gotta follow that, OK come back and see us on this day. Next!' [Here, at Native Health] They take time, they take the time to work with the person and actually do it with a smile on their face, like they'll go out of their way. I've seen them do that with a few people. They've done it for me (Resident, Interview, 13 April 2010).

Led by an Indigenous executive director and board, the agency's mission is 'to improve and promote the physical, mental, emotional and spiritual health of individuals, focusing on the Aboriginal community residing in Greater Vancouver' (Native Health, 2018). The first health service offered by Native Health in 1991 consisted of an evening medical clinic. Since then the expansion of the medical Clinic has been complemented by additional services such as the Positive Outlook Program and a part-time dental program. The Clinic and Drop-in Centre are both open seven days per week and all health services are located with the agency's administration offices on East Hastings Street.<sup>6</sup> Native Health also offers programs at other sites for pregnant women living with HIV.

However, as I complete the dissertation, several programs are in the midst of significant change. In July 2018, Native Health administration closed its daycare due to inadequate funding (Hernandez, 1 March, 2018, 14 June, 2018). Of greater relevance to this study, in the last year, two Clinic physicians – settlers - have been working to set up an independent Indigenous health and healing collective in the area, expected to open Fall, 2018. In May 2018, Vancouver Coastal Health Authority (VCHA), which has been the primary source of funding for the Drop-in Centre announced that it was putting the contract up for tender (T. Braun, personal communication, 3 May, 2018; Hernandez, 1 March 2018). Early August 2018, VCHA announced that the contract for the Drop-in Centre had been awarded to the team setting up the independent Indigenous health centre (R. Vermette, personal communication, 7 August, 2018).

Despite their heavy workloads, many Native Health providers participated in my study because they wanted to better understand residents' experiences of care, and

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<sup>6</sup> Since fieldwork, medical services expanded to include a satellite office on the opposite side of Hastings Street.

they hoped this research would offer insights that could help them strengthen services. Many residents participated in this study – despite their mistrust of people in positions of authority – because they wanted their perspective heard and hoped their insights would be used to improve their experience of health services. The extent to which so many residents opened their lives to me in a setting where their privacy, dignity and trust are so often violated by people in positions of authority required courage. It shows the tenacity of hope and the yearning to be seen and understood. As a nurse, I know how the pressures of care sometimes expose our limitations. The readiness of providers to open their practice to observation also took courage and reflected their commitment to improving services for residents and the strength of community among them within Native Health.

I based my examination of health encounters and fieldwork in two settings: the highly structured setting of the medical clinic (Clinic) and the informal structure of the Positive Outlook Program (Drop-in Centre). Differences in the structures and functions of these settings influenced the enactment of colonial dynamics, offering different insights into the forces that influenced residents' experiences of care and health care encounters. While my independent evaluation of the Patient Self-care Management Study gave me access to Native Health and background data for my doctoral research, that evaluation and an in-depth discussion of the Drop-in Centre are beyond the scope of this dissertation. My analysis in this dissertation focuses on the Clinic.

The public space of the reception area served as the interface between medical services and other, external domains of residents' lives which I refer to as 'the street'. Reception providers (medical office assistants and intake workers) regulated the flow of patients into and through the Clinic. Responsible for the administrative functions needed to support medical care, they also allocated appointments and, given the need to maintain a calm environment, were vigilant to identify and address any resident whose behavior was perceived as a threat to order or safety. In the reception, residents were under great spatial, social, emotional, behavioral and temporal constraints as they often waited up to three hours to see a physician. The large number of provider-resident interactions in this setting and the smallness of this space made it conducive for tracing how the socio-structural context of work and providers' workload influenced their interactions with residents and residents' responses.

Observing medical interactions in the privacy of physicians' office-exam rooms enabled me to analyse health-care interactions between physicians and residents in detail. These observations are complemented by residents' reports of medical care, shared with me outside the Clinic as part of my broader fieldwork and ongoing relationships with residents. In medical encounters, the hierarchies of power between residents and providers, in terms of social, economic, and moral status, were more prominent than in the other settings I examined. I studied how physicians' personhood and experiences produced different styles of practice which influenced the enactment of colonial dynamics in their practice. I was interested in how physicians' understood colonialism and Indigeneity and its relation to residents' lives, identities and struggles, and how they took residents' perspectives, concerns and realities into consideration. In our interviews, I inquired about physicians' backgrounds and reasons for entering medicine in an effort to understand how these and their personhood influenced their styles of practice. Interviews with a number of residents directly after their Clinic visits offered invaluable insights regarding the alignment of physicians' priorities and practices with residents' experiences of these encounters.

As I became more familiar with residents, the emphasis of fieldwork shifted away from Native Health toward observations of their everyday lives in public settings, their homes, and other agencies and institutions within and outside the DTES. I found that interacting with residents outside of Native Health reduced the chance of their being observed or overheard by providers or other residents. This often meant residents were more relaxed which lent a social quality to our interactions and enabled me to observe the influence of other forces like police patrols, the open-air drug market, social networks, and noise on residents' everyday lives and interactions with counterparts and me. Public settings also enabled me to explore the values, beliefs and rationalities underlying behaviors that animated street life and, in this way, offered me more insight into how residents' social realities influenced their experiences of health care.

Socio-spatial differences between Native Health and 'the street' co-existed with the fluidity of interactions across them. For example, relationships between residents on the street spilled into agencies in the form of friendships, debts and other business arrangements. And their relationships with providers inside Native Health also extended out to public, domestic and institutional spaces through various providers' outreach activities and their communication with other external providers about residents' care.

My study, which begins by taking seriously residents' critiques about health care, illuminates the particular ways that colonialism continues to be enacted in health care encounters. But my study also underscores that this reality is complex. For example, on numerous occasions, residents intervened to assist providers by diffusing conflict with other residents, thus demonstrating how caring can also be reciprocal. Many providers echoed residents' critiques about the self-interested motivations of some health studies and services, questioning whose needs these served. There was also more to health encounters than could be explained through residents' critiques, as I observed in the levity and affection that often characterized relationships across Native Health and the close relationships that formed between residents and specific providers.

### **1.3. Methods**

The methodological 'sensitivity' and affinity for collaborative research that I brought to this study were influenced by my experiences as a nurse. Among these, two experiences were significant. The first was my role with a regional public health project on unintentional injuries which included collaborating with providers in several rural health facilities to develop a regional surveillance system to identify local injury patterns. Without funding to compensate local providers for their time, enlisting their participation was contingent on respecting each facility's approach to collecting data and ensuring that local interests in tracking particular injuries were incorporated as the broader surveillance system took form. In many communities, providers' initial assessments of local injury patterns were validated by data. An injury surveillance expert later told me that it was 'impossible' to develop a surveillance system without substantial financial and technical resources. His remark was true within a particular understanding of surveillance systems, but I learned to never doubt the power of collaboration where respect for local knowledge and the affective power of local experience were central. A subsequent study I completed as a public health nursing manager drew my attention to how commonly accepted nursing practices are often experienced in very different ways by the recipients of care. To help understand the low rates of childhood immunization in one community, I conducted a small semi-structured survey to explore parents' experiences of their children's immunization visits. I learned that nurses' use of statistics, which was intended to promote vaccination, left some parents' fearful and reluctant to

immunize their children. The findings of this small study informed my growing fascination in understanding patients' experiences of care.

The ethics and approaches of collaborative methodologies (Lassiter, 2005; Wilson, 2008) which I describe in depth in Chapter 3, informed the methodology for this study. Data for this study was collected through fieldwork which included participant observation, field observation, and a total of 266 semi-structured interviews with 119 participants that ranged in duration from 30 minutes to 2.5 hours. These observations and interviews were not equally divided between health providers and residents. I spent most of my time with residents to understand how their histories and social realities shaped their engagement with health care.

The residents and providers who participated in my study came from diverse backgrounds but were not evenly divided in terms of ancestry: most of the providers I interviewed were settlers, and over half the residents I interviewed were Indigenous. While Native Health had an Indigenous board and executive director, the majority of providers when I conducted fieldwork were settlers. A total of seven Indigenous providers in the agency participated in the study over the period of fieldwork. Given my interest in colonization, I purposely recruited slightly more Indigenous (38) than settler (36) residents to participate in my study, than the approximate ratio of 1 to 9 Indigenous to settler residents living in the DTES (City of Vancouver, 2013).

In addition to interviewing 26 providers at Native Health, I interviewed 25 providers who had been involved in the delivery of care and/or in developing services when the HIV epidemic emerged. These individuals enhanced my understanding of the broader political landscape of health services for residents as these had changed with neoliberal reforms in health care through the epidemic. I began to see how providers could also be harmed by institutions which offered a comparison point for considering the factors that contributed to the warmth of Native Health and many providers' and residents' loyalty to the organization.

Given the significance of the local HIV epidemic and the overlap between health research and health services, I also gathered data from three other sources. First, I analysed all Native Health annual reports from 1995 to 2012, in order to track changes in the Drop-in Centre and Clinic over time. Second, I analysed 253 abstracts of articles

based on health studies that had been conducted by the BC Centre for Excellence (BC-CfE) in HIV in the DTES or included large numbers of residents, from 1998 through 2013. This helped me gain a better understanding of the professional capital derived from the biomedical research industry in the DTES. Toward this end, my review considered the total number of authors, how often they were cited, their institutional affiliation and the specific focus of each study. Abstracts have now been removed from the BC-CfE website. Third, I studied a set of newspaper articles on the HIV epidemic collected by a prominent nurse-administrator at St. Paul's Hospital, housed in the hospital's archive. This archive, which included pertinent articles from 14 August 1985 to 15 December 2007, reflects what a nurse-administrator at the forefront of responding to the epidemic in Vancouver deemed significant over time. The collection offers a sense of immediacy, documenting how the HIV epidemic unfolded and how responses to the DTES changed as antiretroviral medications were developed and as other issues, such as a supervised injection site and the intensification of police surveillance, superseded HIV in capturing media attention.

Data collection stopped when I left the DTES in 2011 and relocated to Victoria, but I remained in touch with many residents through cards at Christmas, letters, visits, occasional phone calls and emails. I noticed a shift in my relationships with several residents after the first year of fieldwork and again, with a smaller set of residents, after fieldwork concluded. The shifts were evidenced by some residents offering more candid information about their lives, their growing readiness to critique my practices, and invitations to visit their homes. A number of residents who were aloof during fieldwork or had consistently declined involvement in the study only *began* speaking with me *after* fieldwork. I did not ask them to explain, but I attribute the shift to the fact that I was more relaxed once data collection had ended. It is possible that my continued contact after fieldwork also showed that I was interested in them as persons and not only as research subjects.

Situating myself reflexively in this study meant I not only observed how colonial processes were enacted in health care encounters, but continually reflected on how my own history, colonial-professional conditioning as a nurse and as a settler shaped my thinking, research practices and relationships with residents. The realizations were often startling and demonstrated the distance that can exist between knowledge and practice. For example, one evening, when three residents agreed to be interviewed about their

friendship. I offered to pick up pizza beforehand and, on asking their preference for toppings, was told they wanted ham and pineapple. When I got to the pizzeria I decided to order a deluxe meat special, presuming residents would ('of course') like more meat since it was more expensive. (I had learned that residents scaled down their meal orders during interviews when they knew I was paying for it, and not the university.) As the meal progressed, one resident picked out the red peppers, a second the pepperoni, and the third the mushrooms. I inquired and learned about their allergies and aversions to specific toppings. I had spent over a year hearing about residents' frustrations with providers who didn't listen and overruled their preferences but it did not prevent me from doing the very same thing. My readiness to discard their request in my need to be seen as generous and (in my mind) to ensure they had the best that I could offer, combined with the fact they silently plucked out the offending ingredients rather than chide me for not listening, exemplified a larger, ongoing dynamic that was, in its essence, colonial.

As discussed in Chapter 3, I found it challenging to balance my dual ethical obligations as a Registered Nurse and anthropologist, and my ethical accountabilities to two groups with very different social and economic realities who were positioned in an unequal and interdependent relationship of power. In keeping with the collaborative ethic of my methodology and to ensure analytic accountability, I informally shared my evolving analysis with various participants throughout the process of writing and formally presented findings to participants before the final version was complete to create room to include their responses.

## **1.4. Theoretical framework**

As I discuss further in Chapter 2, this study is grounded in critiques of colonization that define colonization as an *ongoing* process that continues to enact harm (Alfred, 2009; LaRocque, 2010; Monture-Angus, 2008; Simpson, L. 2011). My reliance on Indigenous scholars for theoretical direction was informed by the striking correspondence of Indigenous and settler residents' critiques of health services to these scholarly critiques of colonization.<sup>7</sup> I contend that critiques of colonization and related

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<sup>7</sup> While the history and systemic nature of colonial harm is not the same for both groups of residents, there is also long history of discriminatory and regulatory responses toward poor people generally (Katz, 1986; Trattner, 1999).

literature about the impacts of colonization for Indigenous Peoples' are relevant to the experiences of all residents' in this study. Scholarly critiques of colonization focus on the impacts for Indigenous Peoples, I see the theoretical points raised by these scholars as pertinent to all residents unless stated otherwise.

Indigenous Peoples have distinct cultures, traditions and histories of contact, but share experiences of colonial oppression. The ongoing impacts of colonization in creating economic, social and health inequities between Indigenous Peoples and settlers in Canada is well documented (Adelson, 2005; Greenwood et al, 2015; Loppie-Reading & Wien, 2009; King et al, 2009; Waldram et al., 1995). Some Indigenous scholars use the term 'post-colonial' (Byrd, 2011; LaRocque, 2010) when writing about contemporary realities for Indigenous Peoples. This term does not negate the ongoing processes of colonial oppression but seeks to draw attention to the post-structural emphasis on deconstructionism and its rejection of the assumptions that imbue modernity (LaRoque, 2010; Simpson & Smith, 2014). Other Indigenous scholars reject the term 'post-colonial' as it implies colonization is a past event and thus trivializes Indigenous Peoples' struggles to resist the continuing impacts of colonialism in their lives (Alfred, 2009; Alfred & Corntassel, 2005; Battiste, 2000; Tuck & Yang, 2012). Throughout this dissertation, I use the term 'colonial' to underscore the persistence of colonial processes and to avoid the use of terminology that might leave readers' with an impression of colonialism as a past event. The term colonial in this study thus encompasses past and present formations.

When Alfred (2009) reminds us that colonization is not the whole story of Indigenous Peoples' lives he is referring to how many of their traditions and cultural ways of being and thinking have survived the devastation of colonialism.<sup>8</sup> Indigenous scholars state Indigenous Peoples ways of relating concentrate on *how* things are done, emphasizing respect for personhood. This includes an ethic of non-interference where respect for self-learning and self-determination are fundamental (Maracle, 2015; Million 2013, 2014; Simpson, L., 2011; Wilson, 2008). The diversity of Indigenous Peoples precludes any singular understanding of personhood, but there are recurrent themes in

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<sup>8</sup> Residents' preferences for particular 'kinds' of health encounters are diverse and while more residents preferred relational styles of practices, there were also settler and Indigenous residents who preferred conventional encounters which emphasized social distance, medical priorities and brevity.

Indigenous scholars' writings: personhood is about relationships and the practices and processes that build and strengthen connection rather than those that promote distance and disconnection. This view of personhood promotes affirmation rather than discipline, guiding rather than telling, and respect for diversity rather than normalizing judgement: points which subsequent chapters show were important to Indigenous and settler residents alike. While relationships occupy a less prominent role in Western understandings of personhood, as discussed in Chapter 2, respect for personhood was prominent in both Indigenous and settler residents' experiences of health care.

Indigenous scholars writings emphasize the importance of Indigenous Peoples cultural sources of vitality and strength in healing the devastating impacts of colonialism. The emphasis on Indigenous ways of being and thinking, in these writings, does not diminish Indigenous involvement with contemporary society. Nishnaabeg scholar Leanne Simpson (2017) states that while Indigenous peoples 'have always been strongly rooted in place, we have also always seen the complicated ways our existence is intrinsically linked to and is influencing global phenomenon' (p. 56). As discussed in Chapter 2, colonialism and capitalism overlap. Indigenous Peoples involvements with capitalism are diverse and often a source political tension within Nations.

Although critiques of colonization usually discuss self-determination in the context of Indigenous Peoples' political struggles for self-governance, Indigenous feminists argue for the dual need to consider political and bodily sovereignty (Maracle, 2015; Simpson, 2017). Parallel processes between the colonization of lands and of bodies were relevant to many residents, Indigenous and settler alike, who sought greater self-determination in health care encounters by having their priorities, understandings and choices respected.

#### **1.4.1. Colonial dynamics**

*Hierarchy is key to their system of control. (Simpson, 2017, p. 88)*

To facilitate my analysis of the ongoing processes of colonialism, I introduce the concept of 'colonial dynamics' which refers to multiple, interacting hierarchies of power that create and sustain asymmetries of power. The focal dynamics in this study include those of time, knowledge (with which I also encompass beliefs, perceptions and rationality), norms, morality, social and economic status.

Just as the vantage of providers limited their understanding of residents' realities and experiences of care, residents' vantage was limited in seeing the factors that influence and constrain providers' responses. The relative positions of these two groups of participants in socially structured gradients of dis/advantage, meant that each had a limited vision of the others' position, which compounded misunderstanding and the difficulties of responding to the other as a person. I have tried to reflect the diversity of perspectives within both groups without reducing the harms of colonial processes as they are enacted and experienced in health care, and without negating the heightened disadvantages for residents created by inequities, ill-health and their reliance on providers for health care.

### **1.4.2. Opening colonial dynamics**

One medical encounter and post-encounter interview with an Indigenous resident, 'Pete', offered me a portal to more clearly seeing how colonial dynamics take shape in situ. Pete had been a long-time patient at the Clinic and had a history of using illicit drugs and drinking alcohol. He had resumed living in the DTES two months earlier following a several-year prison sentence. The physician, 'Dr. Pound', began the encounter by discussing the results of a recent liver function test. During the visit Pete made three references to the stress of living in a shelter and his unsuccessful efforts to obtain housing. Each time, Dr. Pound responded with a cursory acknowledgement then led the visit back to medical matters. The appointment concluded with Dr. Pound asking Pete if he had considered seeing a drug and alcohol counsellor to which he replied, 'No, I don't do drugs no more'. Dr. Pound explained that it might help Pete to have a little support to control his drinking. Pete paused, agreed, and the visit ended. There seemed nothing untoward: the visit was relaxed and Pete readily volunteered information and cracked jokes throughout.

Afterwards, when I asked Pete how he thought the visit had gone, he responded with unexpected intensity: 'I didn't appreciate him telling me to see a drug and alcohol counsellor. I wanted to walk out and say something, but I've learned to control myself – I need to keep this doctor for my HIV'. Surprised, I asked what he would have liked to say to the physician. Without a moment to reflect, he raised his voice, as if Dr. Pound was standing in front of him: 'Fuck off! I don't think you have any right to tell me to see a drug and alcohol counsellor! You can tell that kind of thing to a kid, but I'm 43 years old! They

think I'm still a kid'. Pete had been in systems of authority his entire life, telling me, 'Justice, welfare and health – they're all the same. I can't take the first step on my own. I have to do it their way' (Field Notes, 4 November, 2009).

Dr. Pound's assumptions about Pete's drug and alcohol use left Pete feeling unheard, pre-judged and pushed in a particular direction. He told me: 'I could sense it. I'll be honest with him – I don't go out of my way to drink but he doesn't know that . . . he went right into it without asking any questions about my life [to determine] whether it was appropriate'. I was confused; Pete agreed to the doctor's suggestion, so I asked him about that. 'I did it', he explained, 'to keep the relationship, to make [the doctor] feel he was doing his job and to avoid burning any bridges. I need him for my HIV [care]' (Field Notes, 4 November, 2009).

Within the world of medicine, Dr. Pound's suggestion was appropriate: results of the resident's liver function test were outside the normal range. Physicians and providers in the Drop-in Centre told me that residents tended to under-report their use of drugs and alcohol.<sup>9</sup> Whatever Pete said was secondary to the results of his blood tests and the findings of research. It's possible Pete's reaction reflected some embarrassment of being observed by a woman in a situation where his competence (and hence masculinity) was questioned. But I had also learned that, for many residents, giving advice was only appropriate when it was invited or when a level of rapport had been established and the physician was more familiar with their life. I later interviewed Dr. Pound, and shared my observations to understand the rationale for his practices. Although no longer able to recall the visit I had observed, he explained that he often used 'motivational interviewing', which is an interview technique that purports to assess a patient's readiness to move through the 'stages of change' (Rastegar & Fingerhood, 2005). Dr. Pound's approach did motivate change: It motivated Pete to find another physician.

The observation illustrated colonial dynamics in the prioritization of medical knowledge, Dr. Pound's priorities and perspectives over Pete's priorities and perspectives. For example, during the medical visit Pete had made several references to

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<sup>9</sup> In Heil's (2006) study, when Indigenous participants disclosed their actual intake of alcohol it shocked providers which suggests that under-reporting might be an effort to avoid judgement and get along with providers.

the stress of being homeless, suggesting it was a significant concern, without being able to fully engage the physician's attention. My post-observation interview illustrated how an otherwise unremarkable clinical encounter could have lingering, negative impacts for residents and drew my attention to the amount of emotional work residents do to maintain relationships with providers.

In subsequent chapters, as I examine how colonial dynamics are enacted health care relationships, some repetition is unavoidable.

## 1.5. Main arguments

*[Providers] think they're better – they're not! We all practice the same brushing in the morning, the same positions in sex. . . . It doesn't make anyone any better or any worse, it's who we are. It's about accepting that. Just because you've got a BMW does not make you any better than a guy who doesn't. It's just that you got lucky in life; you were granted some gratuities. You should be happy with that and humble that you have it. (Resident, Interview, 17 April 2011)*

When I set out to examine how the histories and social 'world' of residents interacted with the 'world' of providers, I focused on HIV and expected to find differences in the understandings between providers and residents and between Indigenous and settler participants. Residents faithfully answered my questions about HIV, but biomedical understandings dominated their responses. Thinking I'd asked questions in the wrong way, I developed new questions, but biomedical understandings of HIV continued to prevail. In the course of fieldwork, I learned about many aspects of residents' lives and struggles with health care, including how many felt their experiences, concerns and personhood were invisible to providers, even to those who worked with them on a daily basis. But it was only *after* fieldwork ended, once I was immersed in the process of analysis that I realized that the impact of *inequities* in residents' daily lives and the way inequities shaped their interactions with providers – not HIV – was the main story. While I have worked hard to reflect their experiences accurately, I do not profess to speak 'for' residents nor presume this is the definitive or only story of their experiences with health care.

Based on this analysis, I put forth four main arguments in this dissertation. First, I argue that health research and professional literature based on the DTES does not

adequately account for residents' perspectives. When we take residents' perspectives seriously it draws attention to different aspects of health services and different kinds of interventions to improve care. While residents talked about their struggles in many ways, I found that it was possible to group their narratives into three main critiques of providers: 'they treat you like an Addict',<sup>10</sup> 'they try to control you', and 'they're just in it for the money'. These critiques were informed by residents' broader experiences with systems of authority, and echo key themes in scholarly critiques of colonization related to the harms of colonial stereotypes, governance, and exploitation. Residents' critiques led me to a more fundamental set of findings about the forms and violence of ongoing colonialism and inequities, the contributions and limits of professional norms and responsibilities, the potential for harm contained in providers' therapeutic aims, and the ways personhood influenced residents' experiences of colonial dynamics of care and sense of well-being.

Extending critiques of colonization that focus on Indigenous Peoples to Indigenous *and* settler residents, I make a second argument: residents' critiques demonstrate how colonial processes continue to be enacted in health services and illustrate the specific ways that they harm and intensify residents' suffering. Examining how these processes are comprised of multiple, interacting hierarchies of colonial power which overlap with capitalism, I draw particular attention to how colonialism is re-enacted in the political economy and in the moral dimensions of care. I argue that colonial dispossession of Indigenous Peoples' lands is often re-enacted in a dispossession of personhood in the delivery of care, and that the delivery of care capitalizes residents' suffering in ways that reinforce economic inequities, and perpetuate social suffering. I consider the moralities of colonialism in several respects: in the moral foundations of care, in providers' ethical and therapeutic aims, and in the distance between these and the moral terrain of residents' lives, experiences, and range of choices. I argue this often produces dissonance between providers' therapeutic aims and what is actually seen as possible or desirable by residents. I also extend critiques of colonization by showing that the enactment of colonization in health encounters is more complicated than some analyses allow. For example, I found that residents may experience some form of connection with providers even when feeling alienated from care, and that some

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<sup>10</sup> I capitalize Addict when it refers to a category of person and use small case, addict, when residents use the term descriptively with reference to their past or present use of illicit drugs.

providers want to deliver care in more personal ways but are limited by numerous constraints on their practice.

A systemic lack of respect for residents' personhood leads to my third argument, which extends analysis of the affective harms of colonization by introducing the concept of 'moral violence'. Residents' critiques of health care reflect their general experiences with systems of authority. The pervasive affective impacts of colonialism, such as shame, fear, and despair, have been recognized by many Indigenous scholars (Alfred, 2009; LaRocque, 2010; Million, 2013). Million (2013) attributes these impacts to the normative violence of colonialism, which includes institutional forms of care and projects of moral improvement, such as trauma counselling. While norms and morals often overlap, I contend that normative violence obfuscates the moral dimensions of colonialism and the specific way these contribute to the affective and spiritual harms in residents' sense of 'being'. Inadequate critical examination of these, I argue, facilitates the perpetuation of moral violence through health care. I contend that residents' constant exposure to inequities and to systemic societal and institutional forms of discrimination, governance and exploitation is a form of moral violence that can cause some people to question their fundamental sense of what it means to be a person whose lives have worth.

I contend that the colonial dynamics of health care also dehumanize and harm providers. The colonial conditioning of health services constrained providers' personhood by subordinating their individuality and unique responses to residents' personhood and by subordinating attention to the role of local contexts on residents' suffering to the increasing standardization of practice and reliance on 'evidence-based' approaches. Providers' personhood was also subordinated by the disjunctures between what health care *purports* to offer and what providers' are professionally responsible for and what is *actually* possible for them to deliver or influence. Professional norms and structures discourage providers developing closer relationships with residents. This limits providers' understanding about the relevance and impacts of care in situ, and, when such insights are gained, makes it more difficult for providers to apply these and bring services into better alignment with residents' needs and realities. The latter was evident to me in the particular emphasis placed on 'professional boundaries', which I contend in the DTES functions as an informal way of morally regulating providers and

maintaining social distance, thereby supporting providers' beliefs about the need for professional governance.

My final argument is that the power of personhood can be expressed in ways that temporarily ameliorate the enactment of colonial dynamics or help residents' negotiate the colonial dynamics in health care. Encoded in residents' critiques are their desires to be recognized as persons, to have their knowledge, vitality and agency respected, and to feel providers genuinely care about them. I contend that the fact that many residents had close, supportive relationships with specific providers can be attributed to the generative power of personhood in its ability to temporarily mediate the experience of colonial dynamics by fostering a supportive, intersubjective resonance between persons. In these relationships, which I describe as 'health care alliances', residents' desires were, to differing extents, temporarily realized. In these relationships I found that residents had no hesitation in sharing their bioresources with specific providers. 'Real care', as defined by residents, was something that money couldn't buy. Real care spoke to a *way of being* in relationship that prioritized personhood, presence, and process *or the way things are done*.

The power of personhood – in the sense of recognizing another as a person, in one's individuality and ways of being, and in the intersubjective resonances between people – was not, however, independent of colonial dynamics which comprised the context of health encounters. While the power of personhood had the potential to humanize care it also had the power to intensify the enactment of colonialism. Even when expressed in ways that residents' experienced as supportive, personhood was not an elixir for colonial dynamics, nor a panacea for colonial harms. Since all health care relationships are positioned in larger hierarchies of power, colonial hierarchies continued to operate within alliances, with the result that alliances were always contingent. Even the strongest health care relationships contained the potential to harm and falter. This often created a push/pull tension in relationships where residents may have felt accepted and comfortable with a provider, yet still censored the information they shared for fear of jeopardizing the provider's esteem and support. Similar push/pull tensions were evident in the importance providers placed on 'professional boundaries', where getting to know the resident was necessary to cultivate a relationship but getting *too* close could jeopardize one's professional credibility and risk subjecting them to sanctions. The complexity and messiness of colonialism as it is enacted in health care,

underscores how all of us – residents, providers and myself – are situated in complicated social, economic, political, and medical contexts.

## 1.6. Notes on terminology: ‘Indigenous’ and ‘settler’

During fieldwork I frequently asked Indigenous residents about their understandings, experiences and observations of what it meant to be Aboriginal. I did not then understand the debates around the term, but soon saw that the term was problematic for many Indigenous residents. The difficulties were highlighted in one encounter recorded in the following field note:

Visiting with a resident one day I began inquiring about her experience as an Aboriginal woman and was stopped by her raised voice and fist slamming the table between us: ‘Excuse me! Where did ‘Aboriginal’ come from! I’m not from Australia! I’m a North American [Nation] Indian and’, gesturing to friend, ‘she’s a North American [Nation] Indian. Where the hell did Aboriginal come from?!’<sup>11</sup> (4 April 2011)

The Indigenous resident quoted in this excerpt, like others, identified herself by her Nation. During my interview with an Indigenous Elder, she recalled participating in a meeting with representatives from Health Canada who were talking about Aboriginal people living ‘on’ and ‘off-reserve’. The Elder said the distinction compelled her to inform the officials at one meeting:

If you truly mean what you’re saying, if you’re sincere that we do count, you will stop saying ‘off-reserve’ and you will stop saying ‘urban’, . . . we have our own words. [Turning to me she explained: the word] ‘off-reserve’ kept us separated; that was government terminology, that’s not ours. They’re good at separating, identifying, splitting us up. [Then, continuing with her narrative of the meeting] I said stop it . . . listen! I’m going to tell you one word: Tu’wusht. ‘We are from’. Tu’wusht, we’re from here. I’m from here. (Interview, 31 May 2011)<sup>12</sup>

Obligated to protect participants’ identities, I needed a more generic term when discussing the quotes and contributions of Indigenous participants. Indigenous and settler residents often used the term ‘Native’ when referring to themselves or others with

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<sup>11</sup> The term Aboriginal comes from discussions in 1982 that led to amendments in Canada’s constitution.

<sup>12</sup> The University of British Columbia [UBC] (n.d.) website for the VNHS Tu’wusht garden project, states this term in the Tla’amin Coast Salish dialect means ‘we belong’.

Indigenous descent. I never heard an Indigenous resident describe themselves as 'Indigenous' or 'First Nations', and I rarely heard any use the term 'Aboriginal'. The times I used these terms in my interactions with Indigenous residents, they usually recoiled. I soon switched to using 'Native' in my interactions with residents to reflect their use of the term but continued to use 'Aboriginal' in my writing and in my conversations with providers. Then, during analysis, I became familiar with Indigenous scholars' debates about terminology (see Alfred, 2009; King, 2012; Maracle, 2015; Simpson, A., 2011; Sunseri, 2007, 2010). Although some Indigenous scholars employ 'Aboriginal' in their writing (Monture-Angus, 1999), others reject the term as another form of colonial oppression and erasure, and instead use the term for 'peoplehood' from their own languages (Alfred, 2009; Simpson, L., 2011).

English words that have been used to represent all Indigenous Peoples, such as 'Indian', 'Native', and 'Aboriginal', represent a colonial imposition by negating the diversity of Indigenous Nations and by the irresolvable problems of colonial ideology which insists on classifying people as this or that.<sup>13</sup> Such words are freighted with assumptions that reinforce colonial institutions and relationships (Justice, 2018; Maracle, 2015; Monture-Angus, 1999; Simpson, L., 2008, 2011). Some Indigenous scholars assert that the term 'Indigenous' prioritizes Indigenous Peoples' identities, ways of being, sovereignty, and decolonization (Alfred & Corntassel, 2005; Simpson, L., 2011). This term implies a cultural and political vision grounded in relational ontologies which acknowledge 'that the cosmos is a living being and that the cosmos and all its parts have consciousness' (Miller, 2008, p. 10). Although Indigenous residents shunned 'Indigenous', it also felt untenable to use 'Aboriginal' when referring to scholars like Alfred (2009) and Million (2013) who reject the term as an imposition of colonial violence.

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<sup>13</sup> In the Indian Act of 1876, the government's distinction between 'status Indians' and 'non-status Indians' determined the benefits Indigenous people were eligible for as part of treaty agreements and the forms of governance they were subjected to. The Indian Act erased indigeneity for those living off-reserves and for women married to non-Indigenous men. Amendments to the Indian Act in 1985 and 2011 sought to address gender inequities in status. The status/non-status binary meant that people of mixed-heritage often did not belong in either community and were subjected to discrimination by both Indigenous Peoples and settlers (Barman, 1999; Lawrence, 2004; Perry, 2001). Metis peoples were included in the 1985 amendment to the Constitution and may apply to receive status. In 2013, the CIHR Institute of Aboriginal Peoples' Health declared that 'Aboriginal' should be replaced 'with the more uniting and less colonizing term 'Indigenous' (CIHR/IAPH, 2013).

In the end, I decided to use the term 'Indigenous' when referring to Indigenous providers and residents. My use of 'Indigenous' encompasses people who identify by their specific nations and as First Nations, Metis, and Inuit. Although I include Metis in my definition of indigeneity, I recognize that this, too, is often complicated for those who have mixed ancestry, as several scholars have explained (Barman, 1999; Justice, 2018; Lawrence, 2004). In keeping with the importance of self-determination I accept the claims of individuals who identify as Indigenous, and I do not try to identify a scholar's ethnicity if it is unclear in their own writing. When quoting field data, academic literature, media, policies and research, I leave the signifiers for indigeneity intact.

The evolution in my understanding of indigeneity shifted how I understood Canadian residents who traced their ancestry other parts of the world. Throughout fieldwork, I had used 'non-Aboriginal' or, when talking with residents, 'non-Native' but it no longer seemed appropriate to balance indigeneity with non-indigeneity: the 'non' signifies *an absence*, which jarred with my growing awareness of the colonial violence and inequities resulting from settler's *presence*. For Metis writer Chelsea Vowell (2016), the use of terms prefaced by 'non' communicate the exclusions implicit in colonial beliefs that Indigenous Peoples are 'not-us'. Alternatives to 'settler' in Canada include: Westerners, Canadians, Euro-Canadian, immigrants, or newcomers, or people use terms that reference their ancestry such as Chinese-Canadian and so on. All terms have limitations.

Several Indigenous scholars refer to non-Indigenous inhabitants by the term 'white' (Alfred, 2009; Coulthard, 2007; Grande, 2006; Maracle, 2015). While 'white' can be used to signify 'the psychological and cultural advantages and the economic and political privileges of having white or light coloured skin' (Wray, 2006, p. 5), I was uncomfortable using it given the increasing ethno-racial diversity of people in Canada. I also rejected the use of 'Euro-Canadian'. 'Newcomer' and 'immigrant' because they jarred with the fact that many non-Indigenous people were born in North America. Like Lowman and Barker (2015), I needed a term 'that shift(ed) the frame of reference away from our nation, our claimed territory, and onto our relationships with systems of power, land, and the peoples on whose territory our country exists' (p. 1). In the last 10 years, several scholars have sought to resolve this debate with the term 'settler' (Lowman & Barker, 2015; Regan, 2010; Vowell, 2016). The term 'settler' acknowledges the violent self-justification of colonialism through the erasure of Indigenous Peoples 'as anything

but an empty symbol' (Justice, 2017, p. 10). Cherokee scholar Daniel Health Justice (2018) acknowledges that some settlers formed meaningful alliances with Indigenous people and some have themselves been subjected to colonial violence (for example, with black slaves), but none of these considerations, he writes, negate the simple fact that 'Indigenous Peoples lost lives, lands, and livelihoods as a result of non-Indigenous appropriation of lands and territories' (Justice, 2018, p. 11). While Metis scholar Emma LaRocque (2010) rejects the use 'settler' as a signifier for non-Indigenous Peoples on the basis that 'Native peoples were the original settlers' (p. 7), in this study, I juxtapose 'Indigenous' with 'settler', mindful that any attempt to categorize will remain contentious.

## 1.7. Chapter outline

**Chapter 2** elaborates the theoretical framework of the study with particular attention to the writing of Indigenous scholars. In the first part, I define colonialism and how colonial processes are produced through the construction of social categories and their problem-solving tendencies. I trace historical processes that contributed to the medicalization of Indigenous Peoples' lives, and discuss how beliefs about Indigenous Peoples' pathology continue to justify the medical governance of their lives. The link between self-determination and well-being elaborated by Indigenous scholars provides a foil for understanding how medical governance and the moral aims of care can perpetuate harm and suffering. I also discuss how colonial relationships with Indigenous Peoples are refracted in international humanitarian endeavours in the relationship between affluent and poor nations. In the second part, I elaborate my concept of 'colonial dynamics', which I use to analyze the specific ways that colonialism is enacted in health care, and also introduce the concept of 'moral violence' to extend analysis of the affective and spiritual impacts of colonialism. In the third part, I focus on the importance of personhood, presence and process in Indigenous scholars' writings. With this, I discuss the centrality of relationships to Indigenous understandings of personhood and relate this to Indigenous and settler residents. The interplay between colonialism and personhood in the potential of providers to intensify or ameliorate the colonial dynamics in health care encounters, is the basis for my argument that the generative power of personhood was fundamental to the close, supportive relationships that often formed between residents and providers. I argue that these 'health care alliances'

illustrate how providers temporarily mediate residents' experience of colonial dynamics of care within the existing structures of care.

**Chapter 3** explains the methods used to collect data and how I went about analysis. I also discuss the ethical considerations entailed in this research, including my dual identity as a nurse and anthropologist, my ethical accountabilities to two different but interdependent groups of participants, and the ethical complexities associated with my research.

**Chapter 4** discusses the colonial binary between the 'civilized' and Savage' and how its enactment in colonial beliefs about Indigenous Peoples has been deployed over time to represent the DTES and various groups of poor residents as problems, defined by disorder, immorality and dereliction. These representations, I argue, were reinforced with the HIV epidemic and local health research which helped to reiterate beliefs about Savages in the local figure of the Addict. I contend that these contextual aspects of residents' everyday lives are significant in their experiences of health care. Given the imbrication of health research with services in the DTES, I take a detailed look at how the figure of the Addict is produced through the political economy of the health research industry. I conclude the chapter by contrasting the economic and professional capital vested in health research with the fact that, despite more than two decades of research and funding for related programs, the social conditions and suffering of residents remain unchanged. I argue that health research re-enacts processes entailed in the colonization of Indigenous Peoples' lands at the level of residents' bodies, but also note this is more complex. With neoliberal reforms, numerous researchers have used their projects and skills to offer new and innovative programs or to assist agencies in accessing other funding.

**Chapter 5** details the three main critiques residents make of health services, which attest to their ongoing experience of discrimination ('they treat you like an addict'), governance ('they try to control you') and exploitation ('they're just in it for the money'). Residents' critiques of health care encounters are informed by their broader experiences of interacting with authorities. I argue that health services, like health research, are part of an institutional apparatus that perpetuates residents' suffering, marginalization and experience of inequities. Although colonial beliefs emphasize residents' vulnerability and tend to limit the consideration of their agency to their perceived disorder and potential for

danger, I discuss how many residents regularly expressed their agency in navigating and managing the uncertainties of health encounters in a range of strategies I refer to as 'health work'.

**Chapter 6** examines how colonial dynamics are maintained through the importance that providers attach to professional boundaries and their inattention to residents' boundaries. I contend that the emphasis on boundaries reflects the equally important emphasis many providers placed on developing relationships with residents and the risks more personal forms of care are seen to represent. I also argue that one of the primary functions of this boundary discourse is the moral policing of providers and the institutional need to maintain 'difference'. A lack of attention to residents' boundaries and to the moral and temporal aspects of interactions often resulted in providers violating those boundaries, unaware of the impact or their transgressions. I contrast the temporal dynamics of health care with other temporalities that inform residents' lives and explain how providers' transgressions of residents' boundaries may collide with residents' embodied temporalities of suffering. From this, I argue that the therapeutic temporality of health care is often at odds with the importance many residents attach to an embodied temporality of readiness.

**Chapter 7** introduces the Clinic where I examined interactions in the reception area and within the privacy of physicians' office-exam rooms. Across the Clinic, the industrial and therapeutic temporalities of care and latent beliefs about the dangers of Addicts structured interactions. I examine how reception staff managed the disjuncture between the demand for care and the availability of resources by using a two-step process of filtering, based on the availability of physicians' time and the regulation of residents' behavior in the reception area. Residents' main critique of this setting was the long wait times, which left many feeling that their lives and time didn't matter. Concluding this section, I illustrate how providers' limited understanding of residents' lives, the constraints of their roles, and the norms of professionalism can contribute to conflict. I suggest that greater transparency in communication with residents may mediate this.

**Chapter 8** analyzes medical interactions in physicians' office-exam rooms, focusing on how colonial dynamics are enacted through practices that physicians associated with their 'supportive' role. I briefly discuss how physicians' personhood was expressed in styles of practice and the distinction physicians made between their

'support' and 'regulatory' roles. The bulk of the chapter examines how residents often experienced the support roles as regulatory or judgemental. I discuss physicians' efforts to inform and advise (what residents called 'talking and telling') in relation to the problem-solving tendencies of medicine. Two sections are devoted to the topic of change, looking at how physicians' desires to promote therapeutic aims and claims that they respect residents' choices are more complex. The final section contrasts the focus of medicine on pathology with how residents' understanding of well-being can extend beyond medical parameters in terms of what gives purpose and meaning to their lives.

**Chapter 9**, the conclusion, argues that residents' critiques attest to the affective and spiritual harms which result from their cumulative interactions with authorities and their constant exposure to inequities. I attribute this harm to the moral violence of colonialism. This study illustrates the complicated ways that individuals' personhood can interact with the colonial dynamics of care to intensify, navigate and temporarily mediate residents' experience of colonialism in health care encounters. Given the importance of personhood to residents' positive experiences of health care, I discuss several practices involved in the cultivation of health care alliances. Although my emphasis has focussed on residents' experiences, it is important to recognize that providers are also negatively impacted by the structures of care. I end by encouraging providers to acknowledge the colonial dynamics of health care encounters as a means to more fully and meaningfully engage residents as persons. Doing so will not change the structures or social conditions of their suffering but may improve residents' experiences of health care by greater recognition of the relational medicine entailed in their experiences of 'real care'.

## Chapter 2. Theorizing the colonial present

*LC: [Research shows Indigenous people have higher rates of sickness than non-Indigenous people]*

*Res 1: Yes we do, yes we do.*

*Res 2: That's because of poverty. Poverty.*

*Res 1: No, it's because we don't have the immune system.*

*Res 2: It's poverty.*

*Res 1: And just generation, after generation we're the lowest of the lowest on the totem pole.*

*Res 2: It's just poverty. (Interview, 4 April 2011)*

In this chapter I elaborate the critique of colonization, informed by residents' critiques of health care, which provides the theoretical framework for this study. Before beginning, I want to emphasize that the *language* of the theoretical framework that scholars call 'colonialism' was not shared by residents who experienced such language as irrelevant and/or distant from their everyday lives. The few settler residents I asked about colonialism associated it with indigeneity, and hence as irrelevant to their experiences in the DTES. And most Indigenous residents who participated in this study found the term colonialism alien to their ways of understanding the world and as another form of oppression in its felt reminder of their perceived alterity and social marginalization. As one Indigenous resident explained, 'Native people, in general, feel on the spot when you talk about colonialism – uncomfortable' (Interview, 5 July 2010). When the term was used, this resident said he felt pressured to speak for *all* Indigenous Peoples – something that was at odds with the care many Indigenous residents took to avoid generalizing their views. Indigenous scholars explain that unless authorized to speak for others, one can only report their own experiences (Little Bear, 2000; Simpson, L., 2011; Turner & Simpson, 2008; Wilson, 2008). Another Indigenous resident, who had spent most of his life as a ward of state institutions, felt that discussion about 'colonialism' foreclosed the possibility for him to make choices that opened into a better future. In the following field note from one discussion, he told me, 'you feel like you're doomed before you [try to make a change, so] why bother?' (Field Notes, 23 February, 2010). The only times I heard 'colonization' said without prompting was by providers and

administrators, most of whom were settlers or Indigenous people with post-secondary educations.

However, Indigenous residents' analysis of colonialism was reflected in comments like 'they stole our land'; their mentions of being sent to residential or boarding schools and being forbidden from speaking their language in school; not knowing siblings who were removed and adopted or placed in foster care at birth; or the belief that they were given less expensive generic drugs because they were Indigenous. All residents faced disadvantages, but from what they told me, from what I observed and from what a large literature also argues, Indigenous residents bore a disproportionate burden of exposures to neglect, violence, abuse, discrimination, poverty, social instabilities, educational disruption, and institutional governance throughout their lives. For example, many settler residents reported growing up in homes that were emotionally and physically abusive, but only one who participated in my study reported having been removed from his family and placed in foster care as a child. In contrast, many Indigenous residents in this study reported being placed in foster care, with few reporting they had grown up in their families of origin. My decision to focus on colonization was also based on the illegitimacy of settler occupation and its role in ongoing inequities (Adelson, 2005; Loppie-Reading & Wein, 2009). Although Indigenous Peoples have all been subjected to colonialism, it is also important to recognize the histories, impacts, and experiences of colonialism are diverse. As Cree Metis scholar Emma LaRocque (2010) writes, 'We have all experienced colonial intrusion but we have not all experienced it at the same time or in the same way or to the same degree' (p. 32). As explained in this chapter, I contend that a critique of colonization is also relevant for examining the experiences of poor settler residents. While their lives in the DTES produce a common experience of oppression due to the impacts of poverty, the stigma of illicit drug use, and institutional governance the understandings and experiences of colonialism among and between settlers and Indigenous residents are not the same. To be clear, my critique is of *settler* colonialism. Unlike other forms of colonialism where colonizers primarily focussed on the extraction of resources for the generation of wealth, with settler colonialism, these interests were coupled with the fact that colonizers never left (Heath, 2017). In settler states like Canada, the dispossession of Indigenous Peoples' lands and the imposition of colonial governance are ongoing (Alfred, 2009; Manuel, 2015, 2017; Simpson, 2017).

Numerous researchers have examined the link between colonialism and health inequities in Canada (Adelson, 2005; Greenwood et al, 2015; Waldram et al, 1995) and the colonial dimensions of health care (Browne, 2005, 2007; Million, 2013; O’Neil, 1989; Stevenson, 2014). My study complements this work by focusing on the affective harms of colonialism as they are enacted in health care. Although the affective impacts are shaped by residents’ cumulative experiences with systems of authority and their exposure to inequities, I focus on highlighting how providers both enact and ameliorate affective harm in the delivery of care. Toward this end, the theoretical framework and concepts I present in this analysis aim to illuminate the specific processes of ongoing colonialism in health care encounters.

My critique of colonialism draws from two main bodies of research. Foremost are critiques of colonialism in Canada, with particular attention to the writing of Indigenous scholars. Unlike the abstract nature of many Western theories which are predicated upon the divisions between mind and body, personal and public domains, Indigenous scholars often critique colonization by combining abstract theories with their *personal* experiences which are also recognized as theory (Alfred, 2009; Million, 2014; Monture-Angus, 1999, 2008; Simpson, L., 2011, 2017). Indigenous Peoples, as Nishnaabeg scholar Leanne Simpson (2011) explains, do not separate ‘theorizing’ from one’s emotions, spirit, body and cultural context. Theory is experiential, relational, and grounded in community (Alfred, 2009; Monture-Angus, 1999; Simpson, L., 2011, 2017). As such, theoretical insights may be derived from a variety of sources such as relationships, stories, art, feelings, and bodily responses (Maracle, 2015; Simpson, L., 2011). The contextual and experiential nature of Indigenous-theory generation validates residents’ critiques as serious analyses of health services. Another distinguishing feature in many Indigenous scholars’ work is that their critiques situate the devastation of colonization in the context of Indigenous Peoples’ cultural diversity and enduring sources of vitality (Alfred, 2009; Maracle, 2015; Monture-Angus, 1999; Simpson, L., 2011). I also draw from critiques of medical humanitarianism in the context of international development as I found this literature had many resonances with critiques of colonization, something Kowal (2008) also observes. By highlighting some of these resonances in this chapter, I demonstrate that the colonial dimensions of health care in Canada reflect attributes that are common features of colonialism and humanitarian aid more generally. This second body of literature often frames critiques in terms of

'humanitarianism' or 'development', but both echo the critiques of settler colonialism that inform my study and, together, refract global processes of imperial expansion and capitalism (Hall, 1996; Ince, 2018). I thus take Barnett's (2011) view that understands medical humanitarianism and development as two forms of humanitarian endeavour. Humanitarianism, then, is an encompassing referent for moral projects that aim to alleviate the suffering of others (Redfield, 2005) which, by definition, also includes health care in Canada. However, when citing specific studies, I use the authors' terminology.

In this chapter, I map the theoretical framework for my study in three sections. In the first section, I define 'colonialism' and highlight continuities between the past with the present by drawing on critical research. Guided by residents' three main critiques of health services, I organize this discussion around the production of difference, the imposition of governance, and exploitation. In tracing the persistence of colonial tropes of 'Aboriginality' over time, I highlight how contemporary forms of colonialism invoke race without explicitly referencing it. I then discuss the role of health care in reinforcing colonial governance. With this, I discuss Indigenous scholars' recognition of the link between self-determination and well-being (Ladner, 2009; Million, 2013; Simpson, 2017). I explain my rationales for including capitalism in my understanding of colonialism, for applying a critique of colonialism to understand the experiences of settlers and Indigenous residents alike, and for conceptualizing residents' bodies as bioterritories. Woven through my discussion, I relate processes of colonialism in Canada to critiques of international humanitarianism.

In the second section, I elaborate the concept of 'colonial dynamics', which I use to examine how colonialism continues to be enacted in the delivery of care. Colonial dynamics refer to the interacting hierarchies of power that encode colonial ways of being and thinking in health policies, sciences and structures and are enacted in services and health care relationships. The colonial dynamics of health care relationships were exemplified in conflicts and disjunctures related to time, knowledge and beliefs, norms and morality, and social and economic status. The impacts of colonial dynamics become *visible* in social, material, political and health inequities and in affective responses, such as fear, shame, and the erosion of hope. I argue that the affective impacts of colonialism reflect the moral violence of institutional forms of care and constant exposure to inequities. In the third section, I define and discuss the importance of personhood, presence and process in the writings of Indigenous scholars, which are important to

understand because personhood and colonial dynamics interfuse. I found that the 'power of personhood', while entwined with colonialism, is also influenced by one's culture, social context and experiences. Consequently, the power of personhood can intensify, help navigate and temporarily mediate the colonial dynamics of care.

## 2.1. Defining colonization

I define colonization as an ongoing, structured relationship of power that dispossesses Indigenous Peoples of their lands and resources, subjugates them to colonial rule, and understands these as acts of economic, moral and social development. Colonization is legitimized by a way of thinking that has its roots in an ideology of race that asserts the superiority of Europeans and the inferiority of Indigenous Peoples (Culhane, 1998, 1987; LaRocque, 2010; Youngblood Henderson, 2000).<sup>14</sup> Racial beliefs were encoded in the binary of Europeans' 'civilization' and Indigenous Peoples' 'savagery'. The 'civ/sav' binary, as LaRoque (2010) refers to it, has been tied to a number of other binaries such as strength/weakness, knowledge/ignorance, order/disorder, agency/passivity, vitality/disease, present/past, and urban/rural.

Throughout this chapter, I demonstrate how colonial beliefs about Indigenous Peoples have been taken up in various ways to construe the problems inherent in colonialism as problems of Indigenous Peoples themselves. With it, I highlight how the construction of 'difference' negates diversity and the plurality of meanings attached to phenomenon and the contexts in which meanings are forged. What is important here is how asymmetries of power determine who has and doesn't have the power to assert their definitions and have them accepted as legitimate.

### 2.1.1. Defining difference: From Savage to Addict

*Stereotypes are not attitudes that can be changed by using different terminology. They are windows into the pervasive logics of white supremacy and heteropatriarchy and how they operate through time and*

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<sup>14</sup> During the 19<sup>th</sup> C, poor whites were also sometimes described as a 'race' (Katz, 1986; Trattner, 1999). Colonial representations of alterity were also deployed between European rivals in struggles to assert their dominion over North America (Altamirano-Jimenez, 2008).

*space in Canada on my body and mind as an Indigenous woman.*  
(Simpson, 2017, p. 91)

The supposed inferiority of Indigenous Peoples has been represented in two tropes which show remarkable persistence over time (Battiste, 2000; LaRocque, 2010; Lawrence, 2004). These tropes are the innocent Savage, who needs protection from the corrupting influences of whites, and the barbarian Savage who needs protection from themselves or containment to protect settlers. The innocent/barbarian Savage cross-maps binaries such as worthiness/unworthiness, purity/dereliction, and vulnerability/danger. Both tropes negate the diversity and personhood of Indigenous Peoples and portray them like children. Both tropes consign 'real' Indigenous Peoples to rural areas and 'traditional' lives that can never be seen as fully modern nor, when involved with settler society, recognized as Indigenous. And both tropes condition settlers to respond in two paternalistic modes of either loving/pitying/adoring/and saving Indigenous Peoples or of hating/disciplining/ignoring/and blaming them (Gagne, 2003; LaRocque, 2010; Million, 2013). The deployment of one or the other trope varies to suit the context and exigencies needed to maintain beliefs in racial superiority and the legitimacy of colonial occupation and governance. The malleability of colonial tropes is reflected in Samson's (2003) ethnography of Innu, which documents how early officials' emphasis on their responsibility for Innu quickly shifted to blame when the aims of colonization failed to be realized.

As beliefs about the inferiority of Indigenous Peoples became naturalized as 'common knowledge' (Million, 2013), they were no longer identified with the particular interests of whites (Lawrence, 2004) but construed as objective statements about Indigenous Peoples. This rendered the feeling, thinking, and historically and socially situated Indigenous person socially invisible, and has made it difficult for settlers to recognize Indigenous people they encounter in everyday life as real (Culhane, 2003; LaRocque, 2010; Lawrence, 2004; Pitawanakwat, 2008). The selective in/visibility of how settlers' 'see' Indigenous Peoples includes a selective in/ability to hear what they are saying. The words of Cree activist Harold Cardinal, written in 1969 as Indigenous people began politically mobilizing across Canada to protest colonial governance, remain current:

Talking and listening have been one-way streets. . . . We want the white man to shut up and listen to us, really listen for a change. Some

Canadians listen but [only when Indians say what] white people want to hear . . . such people quit listening when an Indian tries to tell them the hard facts of Indian life (1969/1999, p.10).

Indigenous Peoples have always resisted colonial representations of their lives (Alfred, 2009; Kelm, 1998; LaRocque, 2010; Lux, 2007; Maracle, 2015). For Indigenous scholars, these representations are pathogenic (Alfred, 2009), metastasizing (Alfred & Corntassel, 2005), genocidal (Million, 2013), and radioactive (LaRocque, 2010) lies mobilized in ongoing processes of dispossession, discrimination and economic exploitation (Million, 2013; Simpson, L., 2011).

The Indian Act of 1876 exemplifies both the power of colonial representations and the government's betrayals as Indigenous Peoples did not become aware of the Indian Act until years after it was passed (Lux, 2007). The Indian Act encodes the government's definition of 'Indian' and its dominion over many aspects of Indigenous Peoples' lives in law. In addition to removing Indian peoples' rights to determine who was and wasn't Indigenous, the Act also erased the diversity of Indigenous nations and facilitated colonial governance of Indigenous people as a unitary 'population' (Rifkin, 2014). Although there have been numerous amendments, the Indian Act continues to govern many aspects of Indigenous Peoples' lives, such as where Indigenous Peoples can and can't live, where they can and can't access traditional food sources, and what services they can and can't access. The Indian Act exemplifies the asymmetries of power in colonial relationships and illustrates how categories can simultaneously grant some people access to resources while excluding others.

Colonial ways of seeing continue today. Indigenous Peoples' visibility as persons still, too often, becomes contingent on the extent they fit the image of who they've been constructed to be (Francis, 1992; LaRocque, 2010). In the DTES, residents are visible to external audiences and providers through their poverty, drug use and sickness, but tend to remain invisible as persons (Robertson & Culhane, 2005). This also applies to Indigenous providers and organizations. For example, the Indigenous executive director of Vancouver Native Health Society (Native Health), told me about being in a meeting with settler officials from Health Canada and VCHA who debated what it meant to deliver Aboriginal services, seemingly oblivious to his ancestry, experience and expertise, or that the meeting was held at Native Health, the largest Indigenous health centre in BC.

Officials subsequently decided to direct funds for a service targeting Aboriginal peoples to VCHA on the basis that Native Health wasn't 'sufficiently' Aboriginal.

The elisions and harms of colonial representations of Indigenous Peoples echo critiques of how the subjects of humanitarian initiatives are represented (Butt, 2002; Fassin, 2007; Malkki, 1996). The diverse experiences of 'suffering strangers' (Butt, 2002) are seen to exist to the extent they support external agendas. Subjects' vitality and agency is replaced with representations of their vulnerability and a demand for supplication (Kleinman & Kleinman, 1991). Being a credible object of humanitarian aid depends on being recognized as such. When the signs of subjects' alterity faded, Malkki (1996) found that providers' assessments of subjects' worthiness for assistance decreased. Farmer (1997) argues it is necessary to differentially assign resources because not all suffering is equal and resources are limited. Other scholars have found that when providers assign value to subjects' needs it can intensify the suffering among those who are overlooked, reluctant or unable to ask for help (Berry, 2008; Biehl, 2007; Kleinman et al., 1997).

Representations of suffering subjects function as moral shields for the global political economy of aid. Based on his research with Medicines Sans Frontiers (MSF) Redfield (2006) argues that when physicians spoke as 'witnesses' of suffering, the history, politics and complexities of transnational medical relief disappeared, obscured by the image of the physician. The act of speaking 'for' groups who are identified by their suffering accentuates the visibility and agency of providers while making it more difficult for providers and observers to see their complicity in the conditions that create disadvantage (Butt, 2002). As Barnett (2011) writes, humanitarian initiatives are 'driven as much by our needs as the needs of others' (p. 15). Studies of aid initiatives found providers were often critical of humanitarian efforts generally, but had difficulty seeing how the same dynamics circulated in their own practices (Geissler, 2013; Kennedy, 2004). As this dissertation also found, it is easier for providers to see how the local industry of care undermined residents' independence rather than seeing how similar tendencies were enacted in their practices.

## ***Thinking in categories***

*In a hierarchical society . . . those above must rationalize and justify . . . [their] entitlement . . . as fair and just or see themselves as unjust. (Maracle, 2015, p. 69, 71)*

Colonial ways of thinking take many forms. In this section, I focus on colonial categories and how these are maintained by double standards which create a situation where it becomes virtually impossible for Indigenous Peoples to express their views without it reinforcing colonial stereotypes. I also consider how 'difference' is produced at the interface of care.

Colonial beliefs of racial superiority/inferiority are maintained by double standards that deflect attention from the internal contradictions of social categories while providing ongoing justifications for them. As LaRocque (2010) writes, 'Everything the white man did was legitimized by 'civilization' and everything Indians did was 'explained' by their supposed savagery' (p. 43). Shortcomings in the behaviors of settlers were viewed as exceptions, while the observation of similar behaviors among Indigenous Peoples were generalized to all and taken as evidence of their inferiority. Mohawk anthropologist Audra Simpson (2008), who examined the government's concern with Mohawk people in Kahnawake reserve 'smuggling' tobacco across the Canadian / US border which ran through their reserve, found when whites protested it was seen as an expression of their agency, but when Indigenous Peoples protested it tended to be seen as evidence of their deficiencies. In his study of health care among Inuit, O'Neil (1989) observed when Inuit patients' responses did not conform with providers' expectations, providers attributed it to patients' lack of intelligence, limited education and as justification for their continued tutelary role. This illustrates how double standards create a circular logic that deflects attention from the illegitimacy of colonial occupation and rule while providing an ongoing justification for it.

Double standards also erase the contradictions in colonial rationalities. Kelm (1998), in her history of colonization in BC, found that rates of tuberculosis (TB) among Indigenous Peoples were several times higher than among settlers, which generated widespread public concern about TB spreading to settler communities. Although medical protocols required the isolation of TB patients, when the first TB sanatorium was built in BC in 1907 Indigenous Peoples were denied access.

Categories are also maintained by institutional structures. Browne (2007) found that the stereotypical behaviors attributed to Indigenous patients, such as a reluctance to speak up, were produced by patients' previous encounters with authorities. In other words, commonalities in institutional settings and the responses of various officials *produce* behaviors that fit the stereotypes on which colonialism is based. Similarly, in her study of Hispanic drug users in New Mexico, Garcia (2010) found that stereotypes of the Addict were co-produced by institutional structures and processes. The production of difference is often indirect; for example, increased workloads associated with neoliberal reforms can compound the racializing tendencies of providers. Spitzer (2004), for example, found that nurses avoided Indigenous and immigrant patients because they were perceived as time consuming. In medicine, the increasing reliance on technology, diagnostic algorithms and standardized protocols has been critiqued for increasing the social distance between physicians and patients, reducing their ability to understand and respond to the contingent and particular realities of patients' lives (Human, 2011; Sweet, 2017), and thereby perpetuating the tendency to stereotype patients (Groopman, 2007; Heil, 2006). While the difficulty physicians have in relating to a patient as a 'person' has been identified as a concern for patients of all backgrounds (Radley et al., 2008), it is pronounced when treating patients from ethno-racial minorities, those who are socially marginalized and those living with chronic illnesses (Malat et al., 2006; Spitzer, 2004).

In their examination of a cholera epidemic in Venezuela, Briggs and Briggs (2003) documented how medical profiling of Indigenous and settler populations on the basis of sanitary and unsanitary citizens perpetuated and intensified inequity by diverting attention from social and economic causes of inequity and from providers' and the government's accountabilities. These researchers argue that blaming groups with less access to power provides a mechanism to cope with institutional vulnerabilities but actually renders institutions and providers more vulnerable and less able to perform their functions by locating the blame for social inequities in cultural beliefs and practices rather than social processes.

### ***Problem-solving mode***

*Settler colonialism will always define the issues with a solution that retrenches its own power. (Simpson, 2017, p. 178)*

Europeans' beliefs in their moral responsibility to civilize Indigenous Peoples cast the lives and cultures of Indigenous Peoples as an obstacle to settlement and an object for Christianisation. Scholars argue that problem-solving is a characteristic mode of colonial relationships (Grande, 2006; Tuck & Fine, 2007). Locating 'the problem' of colonialism in Indigenous bodies and communities deflects attention from the illegitimacy of colonial dispossession of lands, the imposition of governance, and the social, material and health inequities that this produces (Razak, 2000). 'The Indian Problem', as it was known colloquially, reflected 'deep-rooted beliefs that the perceived differences between Indians and other Canadians constitute[d] a regrettable situation that need[ed] to be remedied' (Dyck, 1991, p. 1). Although Indigenous Peoples in many areas welcomed or lobbied to gain access to Western medicine, their own understandings of ill health were rarely considered (Daschuck, 2013; Kelm, 1998; Lux, 2007, 2016; Maracle, 2015). Too often, interventions ended up having little relevance to peoples' lives and reinforced their experiences of colonization.

A number of critical researchers have challenged medical approaches taken to improve residents' lives in the DTES (Benoit et al, 2003; Culhane, 2009, 2011; Elliott, 2007; Roe, 2003), but findings from these studies and research-based evaluations of programs even when based in specific agencies (Benoit & Carroll, 2001; Krawczyck et al., 2007), often have little visible influence on services. The inadequacies of services continue to be interpreted as limitations of residents (Roe, 2003).

Providing health care, then, is not simply about solving problems, but carries with it a host of assumptions that shape how problems are defined, what kind of knowledge is seen as relevant, and which groups are seen to have the knowledge and skills to address it. Answers to each of these reflect whose interests take precedence. Ethnographic studies have found that providers define problems in ways that 'fit' available technologies and render local histories and situated meanings invisible (Adelson, 2001, 2007, 2008; O'Neil, 1989; Stevenson, 2014). Inuit patients' dissatisfaction with care in O'Neil's (1989) study was linked to providers' lack of awareness about the differences between theirs and patients' world-views, providers' disinterest in the socio-cultural meaning of patients concerns, and their failure to recognize that, for the Inuit, medical institutions were symbols of ongoing colonialism. While the problem-solving mode of health care is predicated upon providers' abilities to identify and ameliorate suffering, all too often the promised 'improvements' have failed to

materialize and/or intensified suffering (Kelm, 1998; Lux, 2007; O'Neil, 1989), creating a loss of faith in providers' commitment or ability to help (O'Neil, 1989; Stevenson, 2014). In this study, I argue that health services in the DTES are a contested good and exist within a longer history of political struggle.

### **2.1.2. The medicalization of 'difference'**

*It's the way we've medicalized everything – it's the model we've created and it's not working. It's just not working. We're trying to isolate everything in little boxes. We're the biggest enemies as health care people. (Provider, Interview, 10 July 2010)*

A significant factor in ongoing colonization is the medicalization of Indigenous Peoples' lives and bodies. Medicalization refers to the process in which a phenomenon comes to be defined as a medical problem. Viewing something as a medical concern locates the problem within individual bodies and thereby deflects attention from historically conditioned social, economic and political processes that create ill health. While medicalization is a process that can occur anywhere, it has particular salience in Indigenous communities given the associations among medical care, poverty, colonial oppression, and violence (Culhane, 2003; O'Neil, 1989). In this section, I map how Indigenous Peoples came to be synonymous with disease and seen as subjects for medical governance, and how this historical pathologization of indigeneity is currently reproduced through health research.

A convergence of several forces in the 19th and early 20th centuries held particular salience in the pathologization of Indigenous Peoples. By the mid to late 19th century the devastating impacts of disease epidemics among Indigenous Peoples were viewed by officials as evidence of their racial weakness and an inevitable consequence of their rapid transition to Euro-Western 'civilization'. As the developing science of statistics were applied to the study of society and human behavior in the mid-19th century, statistically derived central tendencies became the standard against which bodies, lives and desires were evaluated as 'normal'. Deviation from 'normalcy' became synonymous with pathology. Underlying the use of statistics, Hacking (1990) writes, was 'the notion that one can improve – control – a deviant subpopulation by enumeration and classification' (p. 3). By the late 19th century scientific medicine was preoccupied by the distinction between pathology and normalcy. Belief in the *racial* origins of Indigenous

Peoples' 'predisposition' to diseases shifted to seeing the origins of disease in their *cultural* practices and lifestyles (Lux, 2007, 2016). Although Indigenous Peoples' bodies were weakened by serial epidemics, the rapid rise of tuberculosis was exacerbated by the government in the lack of government funding for reserves, residential schools, and health care; restrictions on Indigenous Peoples mobility and access to food sources; contaminated water sources; and inadequate shelters (Kelm, 1998; Lux, 2007, 2016; Milloy, 1999). Rates of TB In the late 19th and early 20th centuries steadily increased among Indigenous Peoples as rates were declining among settlers (Kelm, 2005, 2007; Lux, 2016). Areas where Indigenous Peoples gathered in numbers, such as reserves or residences for seasonal labour became identified as site of disease and contagion. By the 1940s, as Indigenous Peoples came to be seen as threats to public health, the primary impetus of medical care for Indigenous Peoples was to protect settlers (Kelm, 1998; 2005; Lux, 2016; Perry, 2001).

The persistence of colonial beliefs about Indigenous Peoples' dysfunction and disease have been well documented (Kelm, 2010; Lux, 2016; Stevenson, 2014; Tait, 2000). Waldram (2004) documented how colonial beliefs about Indigenous Peoples have informed mental health theories, research, policies and programmes for Indigenous Peoples over the 20th century. A significant factor, Waldram (2004) argues, is that psychoanalytic frameworks, combined with interests in the personalities of Indigenous Peoples and the psychological impacts of acculturation, led to studies that constructed Indigenous Peoples as inherently pathological. The problematic assumptions of Indigenous Peoples were continually brought forward over time by the scientific practice of citing earlier research. The pathologization of Indigenous Peoples through research, Waldram (2004) argues, can also be attributed to flawed methods, the poor quality of data, a reliance on Western theories for interpretation and the generalization of results.

Metis anthropologist Carolyn Tait (2000) examined how colonial beliefs about Indigenous Peoples' perceived susceptibility to alcohol were reiterated in the construction of fetal alcohol syndrome (FAS). Stereotypes of the 'drunken Indian' have haunted Indigenous Peoples since early contact (Chanteloup, 2002; Waldram, 2004)<sup>15</sup>. These stereotypes have fueled a vast body of medical research examining Indigenous Peoples' alleged biological susceptibility to alcohol and the associated socio-cultural

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<sup>15</sup> The use of alcohol has been identified as a concern by some Indigenous Peoples (Johnson, 2016). My focus here is how it has become construed as a problem for medical management.

context of their drinking patterns (Chanteloup, 2002; Lemert, 1958; Waldram, 2004). While these studies have since been discredited (Fisher, 1987; Leland, 1976),<sup>16</sup> beliefs about Indigenous Peoples' biological predisposition to alcohol continue to inform medical research (i.e., Ehlers & Gizer, 2013; Wade, 2014), health and social services (Killsback, 2012; Maracle, 1993). Tait (2000) found numerous factors selectively profiled Indigenous women at unique risk for FAS, such as the absence of comparative data, a lack of reliable diagnostic tests, and inconsistent medical practices with diagnosis. The biomedical focus on the fetus discounted the historical, socio-economic contexts of risk and failed to consider how this shaped women's needs. A significant factor in the racialization of FAS was the selective focus on Indigenous women who were easier to study given their concentration on reserves, their poverty, and their dependence on social institutions. The fact that most FAS research was conducted on reserves, combined with the fact that alcohol use was a concern for many Indigenous communities, accentuated 'Aboriginality' in findings and constructed Indigenous women as toxic to their fetus. Tait (2000) writes that some Indigenous groups are now concerned that 'fetal alcohol syndrome has become a blanket term to medicalize social problems such as poverty, lack of educational opportunities, structural racism and violence against Aboriginal peoples' (p. 95). FAS demonstrates how contemporary forms of racism can invoke race without explicitly identifying it.

Similar processes have been observed in the DTES (Culhane, 2011; Elliott, 2010; Robertson & Culhane, 2005; Roe, 2003) where poverty, social services, and an open drug-market have spatially contained residents and supported flourishing health research and service industries. The medicalization of poverty and lack of medical researchers' and agencies' interest in residents' perspectives combine to erase residents' experiences of everyday life and health care (Parenthesis added, Culhane, 2011; Robertson & Culhane, 2005). The research industry in the DTES (discussed in greater depth in Chapter 4) reinforces the pathologization of residents by producing a mass of statistics documenting disease, risk and dysfunction (Elliott, 2015). 'Statistical evidence', Elliott (2015) writes, is 'ignored or hidden when ... [it] reflects poorly on the

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<sup>16</sup> These limitations include failing to recognize diversity among and between Indigenous communities and to question the assumption that drinking is a problem. Drinking can also be an important source of sociality, pleasure and coping (Brody, 1971; Heil, 2006; Mears et al., 1981). Dion Stout and Downey (2006) also state that for Indigenous peoples, drinking may be an act of resistance.

state itself, or demands policy and action that is not consistent with the politics of leadership' (p.14). The result is that the diversity, vitality and strengths of Indigenous (and settler) residents, and the social and political forces that produce and maintain their suffering are ignored (Culhane, 2009). The persistence of beliefs about Indigenous Peoples' predisposition to disease are also evident in the fact researchers began monitoring the numbers of Aboriginal people infected with HIV *well before* significant numbers of Indigenous Peoples were infected (Kelm, 2010). Where research was a *response* to growing rates of HIV/AIDS among other groups, high rates of HIV were *expected* among Indigenous Peoples, indicating that the association between Aboriginality and pathology was presumed despite a lack of evidence (Kelm, 2010).

The enduring influence of colonial assumptions in the production of medical science has been demonstrated by several scholars (Anderson, 2006; Epstein, 1996; Farmer, 2006). In their examination of early HIV research in Africa, Packard and Epstein (1991) found that scientific conceptualizations of HIV transmission formed in the absence of data. Racist assumptions about Africans, which permeated scientific discourse, framed HIV as a problem of Africans' sexual practices and reflected researchers' beliefs about the inferiority of African cultures. Foreshadowing Waldram's (2004) research on Aboriginal mental health in Canada, Packard and Epstein (1991) found racial assumptions about HIV in Africa were perpetuated through faulty research designs which accentuated the role of sexual transmission in findings, while ignoring the economic and political conditions that increased exposure to HIV, and the factors that facilitated HIV transmission (such as malnutrition and the use of unsterile needles with vaccination campaigns). 'Difference,' then, continues to be constructed and reaffirmed through health research and services.

### ***The messy complexity of colonial categories***

In critiquing colonial representations of Indigenous Peoples, it's important to recognize that social categories and definitions can also be productive. Adelson (2001) notes that the construct of 'Aboriginality' helped unite Indigenous Peoples across Canada. As well, medical terms can provide vehicles for Indigenous people to communicate aspects of their suffering in ways that can be heard (Adelson, 2001; Million, 2013). For example, Adelson (2008) found that the only way Indigenous women could articulate their suffering in a way that could be recognized by doctors was through

the biomedical discourse of stress, but doing so legitimized inequities by rendering the socio-political context and material conditions that created women's stress invisible. Kleinman et al. (1997) argue that translating local experiences of suffering into medical terms often intensifies suffering by the 'unforeseen and untoward moral, economic, and gender effects of policies and programs, and by actions that end up normalizing social pathology [such as colonialism] or pathologizing the psychophysiology [of systemic racism and violence]' (parentheses added, p. x).

Despite the persistence of colonial categories, there have always been some officials and providers who acknowledged and protested the social, economic and political conditions of Indigenous Peoples' suffering (Dyck, 1991; Kelm, 1998; Lux, 2007, 2016). When Dr. Peter Bryce, the chief medical officer (CMO) for the Department of Indian Affairs (DIA) attributed the appalling conditions, high mortality and disease in schools of Indigenous people to government policies in a 1907 report, he was advised to prepare no further reports and was forcibly retired several years later (Kelm, 1998; Lux, 2016). Such examples challenge the binary of colonizer/colonized but also indicate how the espoused humanitarian aims of state-sponsored health programs can be eclipsed by political interests. The case of Bryce is instructive because it illustrates that when providers challenge the status quo, they too may become casualties of colonial hierarchies of power, regardless of their professional qualifications and status.

This dissertation argues that longstanding colonial beliefs about Indigenous Peoples interacted with the medicalization of drug use in the DTES HIV epidemic, and together gave rise to a particular construction of the Addict, which I argue is a present-day iteration of the Savage that encompasses Indigenous and settler residents alike. In Chapter 4, I trace the role of media and the health research industry in this development. And in Chapter 6 to 9, I build on Garcia's (2010) work that demonstrated how the Addict was co-produced through the structures and temporal pressures of clinical care and in norms that inform professional boundaries.

While constructs of the Addict ignore the agency and humanity of residents it's alter, the Professional, also ignores the vulnerabilities and humanity of providers. Providers' ability to alleviate suffering is seen to be contingent on their professional knowledge and skills. While this is important, I contend that residents may also derive significant benefits from providers' personhood, presence and the relationship. While the

benefits of relationships, as discussed in subsequent chapters, are often reciprocal, the valorization of scientific knowledge and technology in health care results in giving less attention to the importance of personhood and makes it difficult for most providers to consider that the *relationship* with a patient can also be medicine. The subordination of providers' personhood in the 'therapeutics' of care is reiterated in the tendency to subordinate residents' personhood in the delivery of care. This dissertation argues that both parties start to become 'visible' to the other when they feel that their knowledge *and* their personhood are respected. 'Visibility' reflects a felt resonance between persons that is intersubjective and embodied, but in Chapter 8 I explain that for some residents, the recognition of their personhood precedes their ability to consider the providers' individuality, knowledge and desire to help.

### **2.1.3. Governance via medicine**

*Much of what Aboriginal people load into the definition of self-government is not understood by Canadians as having anything to do with governance. (Monture-Angus, 1999, p. 27)*

Government policies for Indigenous Peoples have variously emphasized protection, civilization and assimilation (Tobias, 1976), with medical services playing a significant role in extending and reinforcing these aims in relationships with Indigenous Peoples (Kelm, 1998; Lux, 2016).<sup>17</sup> The delivery of medical care was based on a prevailing assumption that 'First Nations *required* domination to save them from their unsanitary selves' (Kelm, 1998, p. 102). Officials hoped that Aboriginal peoples' experiences of biomedicine would demonstrate settlers' superiority and right to rule (Kelm, 1998). The biophysical focus of medicine on individual bodies facilitates the rationale for governance by deflecting attention from the political, economic and social conditions that produce ill health, and in this way, also sustains the persistence of ill health (Adelson, 2007, 2008). This, in turn, reinforces officials' and providers' beliefs about the continuing need for professional oversight and governance.

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<sup>17</sup> The clause stipulating the provision of a 'medicine chest' on reserves was only included in Treaty 6, oral histories of Indigenous Peoples confirm that in treaty discussions officials often agreed to provide medical care (Lux, 2007; Venne, 1997). Asch's (2014) examination of the extensive notes made by officials involved with negotiating Treaty 4 and 6, also found these congruent with Indigenous Peoples' oral histories. Where Indigenous Peoples understand health care as treaty obligation, the government has always seen the provision of health services for Indigenous Peoples as a voluntary, humanitarian gesture and a temporary arrangement until Indigenous Peoples were able to 'assume responsibility' for their own health care (Lux 2016).

That medical services have been primarily motivated by governance rather than the health of Indigenous Peoples is supported by the fact that the funding and quality of care for Indigenous Peoples has typically been much lower than for settlers (Culhane, 1987; Drees, 2013; Kelm, 1998; Lux, 2016; Milloy, 1999; Shewell, 2004). The fact that health care often *perpetuates* ill health and suffering in the process of trying to address it is well documented (Adelson, 2008; Heil, 2006; Kelm, 1998; Lux, 2016; O'Neil, 1989; Stevenson, 2014). For example, Indian hospitals built following World War II often mixed Indigenous patients with active TB with other patients, rather than co-locating Indigenous TB patients with settler TB patients in public hospitals or sanatoriums (Drees, 2013; Kelm, 1998; Lux, 2016). With the advent of chemotherapy for TB, settlers infected with TB were soon treated on an outpatient basis while Indigenous patients were usually hospitalized for one to two years to monitor their compliance with therapy. Viewing the problem of TB therapy among Indigenous Peoples as a problem of compliance (Lux, 2016) justified the intensification of medical surveillance and management.

Binary thinking, which is characteristic of colonialism, European philosophy and social theory, was reflected in officials' belief that the delivery of medical services would help break Indigenous Peoples' reliance on traditional medicines. Instead, Indigenous Peoples often incorporated Western medicine into their world views and healing practices (Kelm, 1998; Lux, 2007). Similarly, where health care presumes the distinction between health and sickness, Adelson (1998) found Cree in Northern Quebec understood health in a term that spoke to their lives on the land, including both their trials *and* their triumphs. It did not, Adelson explains, 'relate to the biomedical or dualistic sense of health or illness' (p. 10), nor was it a state one sought to attain independent of their relationships with others and the land. It was thus possible for someone to experience physical illness while having a sense of well-being. For Inuit youth in Stevenson's (2014) study of suicide, death was often not the worst thing that could happen. What mattered were relationships with people in the present and the 'life' of one's name, which exceeded the boundaries of physical life by linking individuals to those deceased who carried the same name in the past and those who would carry the name in future. As Heil (2006) found from her study of one Aboriginal community in Australia, providers cannot assume that Aboriginal patients will share or prioritize biomedical understandings.

Although Indigenous Peoples' responses to medical care are diverse (Culhane, 1987; Kelm, 1998), several studies have documented Indigenous Peoples' awareness of the discriminatory and self-serving nature of medical services (Culhane, 1987, 2009; Lux, 2007, 2016; O'Neil, 1989). As already mentioned, one way colonial dynamics continue to be enacted is in providers' failure to recognize that health care continues to represent a form of ongoing colonialism for many Indigenous Peoples (Million, 2013; O'Neil, 1989; Stevenson, 2014). Indigenous Peoples' experience of colonial governance is reinforced as one interacts with authorities across systems. In his ethnography among the Innu, Samson (2003) found that even when there was no direct connection between institutions, similarities in the epistemologies and approaches left Innu with the feeling of a common institutional front arranged against them.

We can see governance in the response to the HIV epidemic in the DTES (discussed in more depth in Chapter 4). Direct Observed Therapy (DOT) programs, which require residents to obtain medications on a daily basis, became an important adjunct to HIV care in the DTES. Elliott (2007) examined how these programs limited residents' mobility and facilitated the medical surveillance and management of their lives, while the historic, social and economic conditions that create ill health remained unaddressed. One physician who participated in my study also worked in a suburb of Vancouver where the geographic dispersal of people who lived with HIV and used illicit drugs made DOT services impractical. He found that his patients, who received their ARVs on a monthly basis to take at home, did just as well as his patients in the DTES. The proliferation of DOT programs in the DTES, where residents are spatially concentrated, and the lack of DOT services in an area where people with similar lifestyles and circumstances are geographically dispersed, suggests that medical governance is more likely to be rationalized as necessary when 'problem groups' are spatially concentrated and in proximity to more affluent groups: a point which echoes the history of colonialization where proximity has nourished settlers' fears of contagion and danger (Kelm, 1998; Lux, 2016).

Medical care also supported the global expansion of colonialism by facilitating the governance of Indigenous Peoples (Anderson, 2006; Vaughan, 1991), and this is particularly evident with epidemics where protecting some groups becomes contingent on restricting the liberties of others (Briggs & Briggs, 2003; Fassin, 2007; Porter, 1999). In fact, some scholars who have examined contemporary aid initiatives contend that

governance is the primary function of humanitarian endeavours (Barnett, 2011; Ferguson, 1994). The problem-solving mode of colonialism, as discussed earlier, is central to governance. Ferguson (1994) found the moral aims of development initiatives, which frame the problems for intervention, were only the visible part of a larger but concealed political apparatus. Just as scholars have observed in the DTES (Benoit et al, 2003; Culhane, 2009), development initiatives systematically exclude local perspectives that might raise historical, social and political issues (Crewe & Harrison, 1998; Ferguson, 2006; Li, 2007). As a result, problems end up being defined in ways that align with experts' skills and technologies.

Analysing one development initiative, Mosse (2005) found that it functioned primarily as a system of representations that maintained alliances between various groups but had little direct connection to what occurred on the ground. Although the initiative failed to achieve its espoused aims, there were other beneficial effects. But because these other effects did not align with the projects' formal aims, they were ignored. Such findings show that humanitarian projects are not only self-serving but also self-perpetuating, irrespective of their impacts. How does one understand the persistence of the colonial 'will to improve' (Li, 2007) despite the fact that projects of social and moral development often fail to achieve their aims? (Orbinski, 2009; Rieff, 2002). Lea (2008) speaks to the tenacious faith in the power of scientific and technological expertise despite evidence of its inadequacies, writing that:

The tropes of interventionary necessity are always underwritten by the promise of one day getting things right. The cunning of remedial logics and the ever present allure of precisely this promise of an abstract future perfect . . . simply feeds the muscle-bound faith in the power of external intervention to amend and improve, operating as a spur to proceed with more of the same (p. x).

In this dissertation, I take care to show how the distribution of health services in the DTES is heavily governed, both by explicit rules and regulations and by implicit norms for both residents and providers.

### ***Self-determination***

*Indigenous freedom means that my sovereignty over my body, mind, spirit and land is affirmed and respected in all of my relationships.*  
(Simpson, 2017, p. 94)

Numerous Indigenous scholars argue there is a fundamental connection between self-determination and well-being (Alfred, 2009; Ladner, 2009; Maracle, 2015; Million, 2013). The desire for better health, Athabaskan scholar Dian Million writes (2013), is an 'ardent attachment' for Indigenous Peoples, but in an Indigenous context, the pursuit of these aims are not understood as therapeutic, normative or imposed by others. Various terms have been used to talk about self-determination, such as 'sovereignty', 'self-governance', 'nationhood', and 'independence'. While the meanings of respective terms are a source of debate (Coulthard, 2014a; Johnson, 2007; Ladner, 2009; Monture-Angus, 1999, 2008; Younging, 2018), I use the term 'self-determination' because it allows more room to acknowledge the interdependent praxis of health services and whether or how residents wish to be involved in their own care. I take Million's (2013) definition of self-determination which means: 'honoring Indigenous Peoples' distinctive ways of looking at the world, integrating these in all relationships between the state and Indigenous Peoples, and *recognizing that Indigenous Peoples alone possess the right to decide what is best* (emphasis added, Million, 2013, p. 4).

Contemporary policies have tended to move away from overtly racialized discourses to those that emphasize recognition, equity and justice. But despite the gloss of enlightened mutuality, researchers have found little has changed (Culhane, 1998; Manuel, 2017; Samson, 2003). Dene scholar Glen Coulthard (2007, 2014b) examined 30 years of state initiatives that claimed to recognize Indigenous Peoples' right to self-determine. He found these projects ended up *reproducing* colonial relationships because the State retained control over the terms and processes for Indigenous Peoples' involvement. Scholars argue that contemporary forms of colonialism, such as those promulgating 'self-determination', appeal to liberal sentiments that make race and racism harder to identify and resist (Alfred & Corntassel, 2005; Coulthard, 2014a; LaRocque, 2010; Million, 2013; Simpson, L., 2011).

When Indigenous Peoples began mobilizing in the 1970s, political self-determination was linked to the articulation of colonial harms. Million (2013) examined how Indigenous leaders used the concept of trauma to communicate the destructive impacts of colonization vis-à-vis residential schools to wider audiences. Although Indigenous leaders' references to trauma included a vision of political sovereignty, when taken up by the State in the Truth and Reconciliation Commission, Indigenous Peoples' testimonies were medicalized as evidence of their pathology. This positioned Indigenous

Peoples as victims and located their healing in the epistemologies and techniques of psych-sciences – a move, Million argues, that ignored the social, economic and political foundations of colonization and re-inscribed stereotypes of Indigenous Peoples' as weak. The medicalization of Indigenous Peoples' experiences undermined concurrent claims for self-determination on the basis they needed to heal before they could self-govern. As Million (2013) writes 'the space of our medicalized diagnosis as victims of trauma is not a site wherein self-determination is practiced or defined'(p. 150).

While a number of studies document the colonial dimensions of health services in Canada, the only studies I located that examined how providers' tried to integrate critiques of colonization with their practice were from Australia (Heil, 2006; Kowal, 2008; Kowal & Paradis, 2005; Lea, 2008). Findings of these studies lend support for Coulthard's (2014b) caution about state-led processes of self-determination when applied within the limited institutional context of health-services. In Australia, even when providers were committed to Aboriginal<sup>18</sup> peoples' self-determination, Lea (2008) found that the prominence of 'health needs' in their practice created a tacit rationale for their continued presence. The state's program to improve Aboriginal peoples' health through self-determination, according to Kowal (2008), was predicated on liberal rationalities that contained an irreconcilable tension in trying to promote health equity while maintaining cultural difference. Providers were thus tasked with trying to improve Aboriginal peoples' health *without* declaring that change was required. When Aboriginal peoples declined health care, Kowal and Paradis (2005) found providers' explanations exaggerated the constraining influence of structure in an effort to see Indigenous Peoples' decisions as rational. In doing this, they dismissed Aboriginal peoples' responses as expressions of their agency. To accept the possibility that Aboriginal peoples had different priorities might have increased the likelihood of providers being able to see their priorities for health as re-enacting colonialism. During the era of 'self-determination', indices of ill health and social instability among Aboriginal people in Northern Australia increased (Lea, 2005). Kowal (2008) attributes this to the fact that the government's focus on health equity overlooked inequities in income, class and education, and failed to consider that understandings of 'self-determination' were influenced by organizational, social and political contexts. Providers' belief in Indigenous Peoples 'right' to good

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<sup>18</sup> I use 'Aboriginal' in keeping with the terminology used in these studies.

health, Kowal (2008) suggests, may be a self-inflicted burden, a comment that hints at the tenacity of colonial beliefs of 'white mans' burden'.

Findings of Australian studies raise questions that have no easy answers. The importance of self-determination in Indigenous scholar's writings includes accountability for one's actions and responsibilities to others (Simpson, L., 2011; Wilson, 2008). This reflects an understanding of self-determination, both in terms of individual agency, but also in terms of relationships with others. In health care relationships patients' accountability is usually framed in terms of their conformity with the temporal, normative and moral dynamics of care – as in conforming with the hours and schedules of services, treating providers' with respect, and supporting treatment plans. What does self-determination mean when the compounding impacts of discrimination, poverty, illicit drug use, reliance on services and fear of eliciting providers' disfavor limits the choices patients' feel able to make? How does one talk about patients' accountability for their behavior when the normative dynamics of services have little ability to recognize the stress and challenges of patients' everyday lives? When there is little space for patients' to express concerns about providers' behavior and practices, providers' beliefs about patients' accountability for their behavior can easily become another way to buttress professional governance. To discount residents' agency is to reproduce notions of their victimhood yet numerous residents in this study stated that during periods of intensive-drug use they lost the capacity for self-care. How do providers respect residents' self-determination in such contexts without it becoming an excuse for social and medical abandonment?

The humanitarian ethos and reliance on expertise which are central to medical governance make it difficult for providers to recognize the harms associated with their efforts to help. In Canada, Stevenson (2014) found that despite the exceptional commitment of providers, bureaucratic forms of care in their preoccupation with biological life negated Inuit cultural understandings and the ongoing impacts of colonialism in local life. In their indifference to Inuit histories of colonization, individuals' personhood, and the importance of relationships, bureaucratic forms of care could be experienced as a burden or, for some, as murderous. Stevenson (2014) came to understand suicide not as a 'problem to be solved' but a wound that attested to the uncertainty of life. From it, she wonders whether such wounds called for an acknowledgement rather than resolution and whether it was possible to care for another

without it being experienced as a demand for their survival. These comments frame suicide and responses to it in binaries: in an acknowledgment *or* a resolution, *in* caring without expectation *or* as a burden. However, to suggest suicide is not a ‘problem’ for communities overwhelmed with serial losses is an affront to their grief and the devastating impact of lost vigor and vitality. And to consider how care might not be experienced as a burden, overlooks the fact that sometimes it is precisely the ‘burden’ of others’ love that carries people through times of despair. Relational accountability in the context of ongoing colonialism involves ongoing struggle in the commitment to maintaining and strengthening connections (Simpson, 2017).

Internationally, as in Canada, humanitarian aid is often critiqued for giving inadequate attention to political and economic contexts and how aid initiatives can exacerbate suffering (Barnett, 2011; Kennedy, 2004; Nguyen, 2005; Nguyen et al, 2007; Redfield, 2005; Ticktin, 2006). Ticktin (2006) argued that by prioritizing sentiment, humanitarian initiatives tend to give little attention to human rights and thereby intensifying inequities and creating new forms of suffering. In her study of Hutu refugee camps, Malkki (1996) found that the emphasis on saving lives prolonged peoples’ suffering because aid workers were unable to address the political conditions of exile. The universal ARV treatment program in Mozambique examined by Kalofonos (2010) kept people alive but exacerbated hunger, causing some Mozambicans to complain that ARV programs ‘inflicted a cruel form of torture’ (p. 364). The well-known medical relief organization Medicine Sans Frontiers (MSF) consciously frames humanitarian interventions within a politics of rights and dignity. However, Redfield’s (2005) study of MSF found providers’ ‘technical ability is never quite able to satisfy their ethical desire. The more they save bodies within limited conditions, the starker the contrast between minimal existence and fully formed life’ (p. 347). Aid may keep people alive but does not address the conditions that enable people to flourish and live with dignity. This does not minimize the value of keeping people alive but chastens the moralities of medical humanitarianism. The political economy of suffering and the positioning of humanitarian efforts within the structures of global capitalism with its insatiable appetite for the economic growth of some, may only – *at best* – allow bare life for others.

In addition to overlooking the harms, humanitarian endeavours also overlook the agency of subjects. Anthropologists have found that subjects have their own reasons for participating in aid initiatives (Mosse, 2005; Nguyen et al, 2007; Pigg, 1992, 2001).

Studies in the DTES have also documented residents' agency despite their social challenges and the governance of their lives (Culhane, 2003, 2011; Robertson & Culhane, 2005). What I draw attention to now, however, are studies that attest to patients' efforts to have their concerns taken seriously by providers (Malat et al., 2006; Werner & Maltreud, 2003). Malat et al. (2006) found that patients who were socially marginalized by poverty, race and gender worked harder to present themselves positively to physicians than more privileged patients. Werner and Maltreud (2003) found the challenge was intensified for women given the delicate balance in not appearing too strong, too weak, too sick, too smart or disorganized. In Malat et al.'s (2006) study, black patients who were more assertive received better care. Based on their analysis, these researchers suggest that the work patients do to receive care and be taken seriously may reduce the cognitive resources available for other tasks, like remembering to ask questions or retaining information discussed. Other studies show that patients' efforts to present themselves in a positive way, (which I refer to as 'health work' and discuss at length in Chapter 5), has a significant bearing on physicians' responses. In Street et al.'s (2007) study, physicians were more patient-centred with patients who expressed positive affect, were involved with their care, and were less contentious. Hall et al. (2002) found that patients who felt liked by their physicians had better health, more favorable affective states following the visit, and felt better about the visit. Time pressures of clinical visits were a significant constraint on patients' health work (Malat et al., 2006). In their study of hospitalized Indigenous patients, Browne and Fiske (2001), found that they often adopted strategies to enlist providers' good will, effect better care and manage the uncertainties of health encounters. Health work is not limited to patients: Another study by Browne (2007) found that Indigenous nurses also worked to smooth relationships with colleagues and to temper colleagues' discriminatory reactions toward Indigenous patients. None of these studies, however, considered the possibility that health work may have negative impacts on patients' care.

### ***What this study contributes***

My study builds on existing research – of health care in relation to governance – by analyzing how providers adopt governmental strategies to manage a limited supply of resources relative to the demand for their services and the availability of their time. Residents were more likely to gain access to limited resources based not only on the perceived acuity of their health concerns, but the extent they were able to bring their

lives and behaviors into alignment with governance structures, and on the efficacy of their health work. In Chapter 5, I describe the health work residents deployed to build and maintain relationships with providers and enlist their assistance. Residents' health work was not only about having their concerns taken seriously but also about overcoming stereotypes of Addicts in being seen as persons.

I also build on analyses of colonial governance by highlighting the multiplicity of constraints on providers, with particular attention to their understanding and use of professional boundaries. This study argues that providers who challenge professional conventions by trying to bring care into greater alignment with residents' needs and social realities may be morally policed by their peers and health care institutions which encourages their conformity with norms about 'maintaining boundaries'.

I discuss how residents may experience such health-care governance in complex and contradictory ways. Some residents' critiqued providers' governmental tendencies yet formed close relationships with providers who had more paternalistic styles of practice and experienced such practices as caring. While some providers chafed at the constraints imposed by health care norms, others invoked stereotypes of the Addict in response to perceived threats to their authority or feelings of personal vulnerability. Thus, while I generally argue that more attention should be given to respecting residents' self-determination, whether, when and how this is addressed depends on the exigencies of each encounter and relationship.

### ***Exploitation***

*Capitalism is a vampire on our cultures. . . . Our blood is its currency.*  
(Million, 2013, p. 179)

When talking about the overlap between colonialism and global capitalism it's important differentiate international relationships from the extractive and exploitive economy of capitalism. Indigenous Peoples have a long history of 'place-based' internationalism based on trading and treaty relationships with many Nations, but these were based on a 'deep reciprocity' between groups rather than capitalist notions of private property (Simpson, 2017). 'To many American Indians', writes Pascua Yaqui Eddie Brown (2013), 'the term "capitalism" conjures up images of colonial expansion and exploitation of tribal nations' (p. 123).

The close connection between colonialism and capitalism, while overlooked in much academic research and theorizing about colonization and inequities, is gaining increasing attention from Indigenous scholars (Coulthard, 2014a, 2014b; Million, 2013; Simpson, 2017). Unlike Marxian analyses of capitalism, which attribute inequities in wealth to the exploitation of workers' labour, Indigenous scholars and others argue that *colonial-capitalism* generates wealth through the dispossession and exploitation of Indigenous Peoples' lands, resources (Coulthard, 2014a, 2014b; Ince, 2018; Manuel, 2015, 2017) and livelihoods (Harvey, 2003; Veracini 2016). Irrespective of the focus (i.e., education, health, land-claims) and irrespective of the application (i.e., law, policy, research), numerous critical scholars have shown that state-led initiatives purporting to promote equity and improve Indigenous Peoples lives, generate new economies of whom settlers are the primary beneficiaries and, in the process, maintain asymmetries of power (Coulthard, 2014a, 2014b; Ladner, 2009; Million, 2013; Samson, 2003; Simpson, L., 2011). Some scholars, like Simpson (2017) and Manuel (2015) envision an alternative to capitalism in trade relationships modelled on Indigenous values. But Indigenous Peoples engagement with capitalism is diverse (Manuel, 2015) as evidenced by responses to the proposed expansion of the Kinder Morgan pipeline, where many Nations are resisting its use of and negative impacts for unceded territories (Lukas, 16 October, 2017), while at least one Nation has publically endorsed it in hopes of generating employment for the community (Gerszak, 4 May, 2018).

Indigenous scholars recognize the complexities of life within Indigenous communities, but their analyses of colonial – capitalism focusses on the racist foundations of the Canadian state and the profound, enduring asymmetries where Indigenous Peoples 'were reduced by settlers to a tiny patchwork of reserves that consist of only 0.2 per cent of the landmass of Canada ... with settlers claiming 99.8 per cent for themselves' (Manuel, 2017, p. 70). The emphasis on land and Indigenous sovereignty is foundational, but there is a lack of attention to the exploitation of bodies and suffering that has always – also - formed the basis of helping professions in Canadian colonial policy especially in rural areas where it was important to maintain high numbers of Indigenous people in Indian hospitals and schools (Lux, 2016; Millroy, 1999).

Scholars explain that Indigenous Peoples understand the land as a field of reciprocal relationships that shapes their ways of being and thinking and sustains life (Coulthard, 2014b; Maracle, 2015; Simpson, L., 2011). In the Dogrib dialect of

Coulthard's (2014b) Dene community, the land 'is translated in relational terms as that which encompasses not only the land (understood as material), but also people and animals, rocks and trees, lakes and rivers, and so on' (Parenthesis added, p. 61). In contrast, colonialism takes an instrumental view of land, seeing it as a material resource for the generation of wealth (Coulthard, 2014b; Harry, 2001) – something to own and develop (Blomley, 2004). When the land is understood as property, an individual's relationship to the land is reduced to that of an owner (Tuck & Yang, 2012). Colonial dispossession of the land plays a crucial role in fracturing the relationships that constitute Indigenous Peoples' identity, community and well-being. For some Indigenous scholars, the fundamental violence of colonialism lies in producing multiple forms of disconnection (Alfred, 2009; Monture-Angus, 1999). For others, Indigenous feminists, colonialism is highly gendered in the violence of heteropatriarchy and its myriad devastating impacts for Indigenous women's bodies (Maracle, 2015; Simpson, 2017; Stote, 2015).

The instrumental nature of colonial understandings of the land parallel the instrumentality of health care insofar as the temporalities, structures and medical parameters of care give little if any attention to patients' histories, social contexts, experiential knowledge, and personhood (O'Neil, 1989; Stevenson, 2014). If Indigenous understandings of the land encompass people, as expressed in the statement 'we are the land' (Miller, 2008), then Indigenous people also constitute territories – *bioterritories* – a point supported by Indigenous feminists who emphasize the need to consider sovereignty of Indigenous peoples lands *and* their bodies (Simpson, 2017; Maracle, 2015). I apply the concept of bodies as territories to support my argument about the importance of residents' self-determination in health care, mindful that for Simpson (2017), efforts to improve health care without addressing the

politics of land and body dispossession serves only to reinforce settler colonialism, because it doesn't stop the system that causes the harm in the first place while also creating the opportunity for neoliberalism to benevolently provide just enough ill-conceived programming and 'funding' to keep us in a constant state of crisis, which inevitably they market as our fault (p. 42).

The significance of this argument for Indigenous residents is not the same as for settler residents, given Indigenous Peoples ancestral occupation of lands and world views. However, the political, economic and social forces that are entailed in the

marginalization of settler residents often leave them with no material wealth other than that represented by their bodies and stories (Elliott, 2007; Tomaselli, 2003), and with little political influence other than that exercised over their bodies and stories. In this vein, then, when health providers deliver care, they enter residents' bioterritories, access their bioresources and, in the process, capitalize their bioresources. In this dissertation, I use the term 'bioresources' as an encompassing referent in discussing how residents' ill health, suffering, biotic material, biodata, personal stories and experiences are used in health research and health care.

### ***Bodily dispossession***

*The situation for the Indian people, as bad as it is, has resulted largely from good intentions. (Cardinal, 1969/1999, p. 8)*

Colonial dispossession is usually discussed in terms of Indigenous Peoples' expulsion from their lands for settlement and the corresponding generation of inequities in wealth. In health care, dispossession is less about expulsion from health care sites than the processes and practices that disrespect or are indifferent to residents' personhood and right to self-determine. The elision of patients' personhood in medical care is not unique to this study but is more of a concern for patients who are marginalized by ethnicity, poverty and chronic illnesses (Human, 2011; Malat et al., 2006). Several studies have framed this as the tension between the 'medical voice' and the patients' 'life-world' (Barry et al., 2001; Carpenter-Song, 2011; Katz & Shotter, 1996). I understand it as a form of 'dispossession' because the elision or 'stripping' of personhood that is embedded in the process of medical diagnosis (Barry et al., 2001; Groopman, 2007), is the basis for the capitalization and industrial efficiency of medical services, and is a prominent source of harm as evidenced in residents' critiques of health care. Whether or how physicians address patients' personhood and social realities is a matter of their discretion and does not affect the material benefits that they and other providers derive from care.

The concept of biovalue, introduced by Rose (2006), describes how the vital processes of life have been capitalized to create new markets. In the DTES, as Elliott (2007) observed, residents' economic value lies in their perceived *lack* of vitality; through medical research, their biodata is incorporated into transnational circuits of research. That residents' economic value to society as workers is far less than the economic value

their bioresources represent to researchers and providers (Roe, 2009) is not lost on many residents (Culhane, 2011; Elliott, 2010).

Critiques of humanitarian aid argue that humanitarian crises have become economic resources for global industries of research, compassion, and concern. Initiatives that start off with the narrow objective of delivering emergency aid to save lives frequently expand operations to address social, economic and political conditions (Crewe & Harrison, 1998; Rieff, 2002). Escobar (1995) argues that the imbrication of economic and political interests with development initiatives continually expands the control and exploitation of Third World countries and perpetuates global, political and economic asymmetries between 'West' (expert) and 'Rest' (subject) populations and nations. These insights have been useful for helping me understand residents' critiques of health care, especially the belief that providers are economically profiting from their suffering.

### ***The moral value of health care***

My research builds on the foregoing in arguing that the presumed 'good' of health care often renders residents' experiences and the negative impacts of care invisible or irrelevant. The concept of biovalue helps explain how health services for socially marginalized groups can perpetuate economic inequities through the capitalization of their bodies, but it does not account for how the capitalization of their bioresources is underwritten by the moral value ascribed to health research and services. Residents' experiences made clear to me that providers benefit economically *regardless* of whether they alleviate or intensify residents' suffering. In other words, the moral value attached to the delivery of health services does not depend on its success.<sup>19</sup> This may sound strange since one attribute of the neoliberal shift in health care and the associated emphasis on 'evidence-based' approaches, is a preoccupation with evaluating service-impacts. These evaluations tend to be driven by priorities and targets that are identified by administrators, policy makers and professionals and influenced by neoliberal logics of cost-savings and efficiency. In the DTES this perpetuates the lack of serious attention to residents' experiences of care and their recommendations for improving services (Benoit & Carroll 2001; Culhane, 2011).

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<sup>19</sup> I thank Erin Martineau for drawing my attention to the theoretical significance of this and thank Roberto Abadie and Martha Lincoln for sharing helpful resources to develop my argument.

## 2.2. Colonial dynamics and impacts

*The starting point of policy makers and program builders needs to be the understanding that they can [and often unwillingly do] do harm, . . . that [the] potential for harm lies latent in the institutional structures that have been authorized to respond to human problems . . . [and in] the best intentioned professionals (Kleinman & Kleinman, 1997, p. 18).*

In this study I examine how colonization continues to be enacted in health care through what I call colonial dynamics, which I define as the interacting hierarchies of power that are the context in which health services are developed and delivered, and in which health care relationships occur. The term 'colonial dynamic' aims to highlight continuities between broader social processes and the level of care, and to underscore continuities between the past and present. The term 'dynamic' reflects the malleability of colonialism and its ability to assume different faces in various contexts (Alfred & Corntassel, 2005). My focus on the continuities of colonial dynamics is deliberate and supports my broader argument that colonialism is ongoing. However, as I examine the interplay between colonial dynamics, personhood and relationships in specific contexts, I draw attention to the discontinuities, contradictions and ambiguities in how colonial dynamics are enacted in health encounters.

While colonial dynamics are co-constituted, mutually reinforcing, and often overlapping, I must explain them here in a linear fashion, a process that inevitably diminishes their interaction and complexity.

### 2.2.1. Hierarchies of power

Colonial dynamics reinforce particular beliefs about differences, which see certain ways of knowing and being as superior and others inferior. The hierarchies of colonial power I observed in this study worked within the following domains: knowledge (including beliefs, perceptions and rationalities), time, norms, morality, social and economic status. I saw colonial dynamics in the structures, conventions and practices that sustained professional distance and made it more difficult for providers to interact with residents as persons. I discuss in Chapter 7 and 8, for example, how the highly structured clinical setting prioritized efficiency and productivity, which reduced providers' ability to take time to better understand residents' perspectives and desires. Colonial dynamics were compounded by the spatialization of many health services, where most

encounters occur within the walls of agencies, and by the fact most providers lived outside the DTES. Together, this means that many providers have little exposure to and limited understanding of residents' everyday lives.

I also identified colonial dynamics by noticing the selective in/visibilities and double standards of providers' perspectives. While all social positions illuminate some phenomena while concealing others (Haraway, 1988), colonial dynamics were evident when the in/visibilities and double standards of care buttressed providers' power and authority. Providers often talked about the skills they used to develop relationships but rarely acknowledged that residents *also* worked to build relationships and that the strategies they used were often the same. Although providers justified their relational work in the interest of delivering care, if they sensed residents' health work, such efforts tended to be construed as the 'manipulative', drug-seeking behavior of Addicts.

Colonial dynamics were also evident in whose values, time, moralities and perspectives drove encounters and whose were silenced or secondary. For example, residents were required to align their lives with the hours and schedules of health services, both incurring long waits and often feeling rushed through their time with physicians. I also saw colonial dynamics at work in the structures and practices that silenced or alienated residents and evoked feelings of fear, shame, and/or injustice. As I explored patterns in providers' behaviors and interview responses, I often saw 'the colonial' in the broader forces, norms and structures that conditioned their responses.

### **2.2.2. The complexity of colonial dynamics**

In practice, identifying colonial dynamics was extremely messy, especially as their enactment in practice was not always or necessarily at odds with residents' experiences and needs. In some situations, it was necessary and appropriate for providers to exercise the power vested in their roles, such as when residents were too ill to engage in care, when residents wanted providers to 'take charge', and when residents verbally or physically threatened other patients or providers. The paternalism of providers' practice did not preclude the formation of health alliances, even among residents who generally eschewed such tendencies. And the enactment or amelioration of colonial dynamics in providers' relationships with residents, did not necessarily have any bearing in their practice in other roles. Where some residents resisted the regulation

of their lives, as with requirements of the methadone maintenance therapy or ARVs, other residents credited these interventions with stabilizing or saving their lives. Although most residents resented being treated like Addicts, some deprecated other residents for being Addicts or rationalized their own behaviors on the basis that they were Addicts. Residents' resistance to being treated 'like Addicts' coexisted with the fact that some did try to obtain drugs for non-therapeutic uses or occasionally took items from the Drop-in or providers' offices without asking. I also observed double standards among residents who expected providers to know what they needed while resenting those who asked too many questions. The influence of colonial dynamics is also not unilateral. I observed these dynamics in the social hierarchies of street-life where, as an Indigenous resident frequently told me, one was either 'predator' or 'prey' and when residents expressed contempt for counterparts who used certain types of drugs or were perceived as weak. How does a provider's abrupt response to a resident come to be understood as an expression of colonial dynamics versus their personal responses to stress? If a resident prefers quick and medically focused interactions, are the dynamics of the encounter any less colonial? How does one assess colonial dynamics in public settings like a clinic reception area, when some residents experience a provider's actions as oppressive and others see it as necessary or helpful? If residents describe being able to relax and be themselves with a provider, does it mean that the relationship is no longer influenced by colonial dynamics? Is it fair to talk about the colonial dynamics of HIV care when some patients are helped and others report being alienated? As well, colonial dynamics are not always aligned. As discussed in Chapter 8, when physicians' apply their knowledge and technologies in a thorough medical investigation of resident-identified concerns it often left the resident feeling seen and heard. The problem, in terms of ongoing colonialism, could often be attributed to the moral dynamics of care in providers' filtering residents' concerns and choices according to the providers' values and priorities. Similarly, many of the situations that taxed residents and providers, such as long-wait times and heavy workloads, are common to health services outside the area. Is it still accurate, then, to talk about the colonial dynamics of health services? I argue that it is because the ways providers enact their desires to help are shaped by larger structures, discourses, and moralities that are rooted in colonial assumptions and hierarchies of power which privilege certain groups' ways of thinking and being. In saying this, I again note the important distinction in the analysis of residents and providers as 'populations' or collectives (like professional groupings), and in the analysis of diverse individuals and

relationships positioned within larger and unequal structures. However, as Krieger (2011) observes levels and scales are not discrete. Broader forces, such as regulations, have a direct influence on health care relationships and local realities can have a wider influence, such as physicians who changed their practices for prescribing pain medication in response to having their faith in the veracity of residents' pain betrayed.

This dissertation also shows that an analysis of colonial dynamics must consider the personal dimension of health care relationships. I observed how providers' responses to residents could intensify residents' experiences of colonial dynamics but also witnessed responses that promoted connection, good feeling and enabled residents to relax and feel treated 'like normal people'. This personal dimension was also idiosyncratic: when providers started to recognize the ideological aspects of health care on sensing they had violated residents' privacy or through experiences that caused them to critically reflect on the conventions of care that it could lead to practices which subsequently mediated residents' experiences of the hierarchies of power. The affective dimension of encounters and relationships, I found, were often important for residents and providers' alike. This suggested to me that personhood, while entangled with colonial dynamics, was also more. The personal dimension of encounters, in this respect, reflected the generative – humanizing – power of personhood. When residents' personhood was recognized by providers, they were less likely to feel judged. And for many providers, being able to interact with residents more personal ways was important to their job satisfaction. Providers' ability to recognize residents' personhood was itself influenced by the structures of care and how they felt respected as persons themselves and able to express their individuality with work. It could also be influenced by experiences that caused providers to critically reflect on the taken-for-granted conventions of health care. What, where and how I observed the power of personhood in these ways is the focus of the concluding chapter.

### **2.2.3. Affective impacts: Normative and moral violence**

*To me, this colonial shame felt like not only a tremendous burden to carry, but it also felt displaced. We are not shameful people. We have done nothing wrong; . . . shame can only take hold when we are disconnected from the stories of resistance within our own families and communities. (Simpson, L., 2011, p. 14)*

The impacts of inequity on the health and well-being of the poor have been examined by many anthropologists (Desjarlais, 2000; Farmer, 1997, 2003; Nguyen, 2003; Scheper-Hughes, 1992). The term 'structural violence', originally conceptualized by Johan Galtung in 1969 (De Maio & Ansell, in press), has been advanced through the work of Paul Farmer (1997) who uses it to describe 'how various large-scale social forces come to be translated into personal distress and disease' (p. 261). Structural violence draws attention to the systemic forces that become enacted in policies and institutional practices which produce disparities in social, economic and health status for the poor but as De Maio and Ansell (in press) argue, the term is theoretically imprecise. For my study, a specific challenge with Farmer's use of structural violence is that it gives little attention to how it is enacted in medical endeavours, which exempts the moralities of medical humanitarianism. While structural violence illuminates some aspects of residents' suffering it fails to account for the normative discourses of pathology and the moral aims 'to improve' Indigenous Peoples. For it is the normative and moral nexus of racial beliefs about Indigenous Peoples and the moral aims of improvement that are fundamental to colonial dispossession and governance, and the pervasive affective impacts which register in fear, shame, anger and despair among Indigenous Peoples (Alfred, 2009; Graveline, 2004; LaRocque, 2010; Million, 2013; Simpson, L., 2011). In her study of Hispanic people in New Mexico, Garcia (2010) described how dispossession of their land produced a chronic state of mourning that Hispanos mediated through the use of drugs. Stevenson (2014) found some Inuit mourned many years after relatives with TB were taken from the community for medical treatment. In health care, the affective impacts of colonialism are also documented in studies of Indigenous and settler patients who reported fears of providers' rejection, discrimination, and misunderstanding (Baker et al, 2000; Benoit & Carroll, 2001; Browne et al., 2011; McCall et al., 2009).

Several Indigenous scholars have attributed the affective impacts of colonialism to the internalization of colonial ways of thinking (Alfred, 2009; LaRocque, 2010), something Leanne Simpson (2011) conceptualizes as responses to 'cognitive imperialism'. Million (2013) writes that affect impacts of colonization include more than emotion and involves the 'larger charged sociality, traces of a vitality of being, prior to and not reducible to thought. . . . Affect eludes, [and is] present before and beyond any singular consciousness: . . . affect might be imperceptible or incite or mobilize intensities

of any possibility in any situation' (p. 49). Million (2013) attributes the affective harms of colonization to the normative violence of the Indian Act and colonial power relations. I understand normative violence as the naturalized, systemic denigration of Indigenous Peoples' ways of being and thinking. It is encoded in the medicalization of Indigenous Peoples' lives and the corresponding emphasis health services place on their vulnerability. The potential for normative violence is contained in what providers come to understand as normal, necessary, rational, and true.

Scholarly theorizing of normative violence resonated with my sense that there was more to the deleterious impacts of health care for residents than was expressed in their critiques alone or that could be accounted for by the concept of structural violence. While normative violence accounted for residents' internalization of beliefs that they were deficient or inadequate and the shame and fear these beliefs could elicit when interacting with authorities, the concept *normative* violence seemed inadequate to account for the cumulative, affective and spiritual - *ontological* - impacts of colonialism and inequities on many residents' sense of worth, hope and place in the world. It was difficult for me to consider the degradation of self and personhood, described by some residents and discussed in the concluding chapter, as a response to normative violence when the wounding was also moral and spiritual. What I mean is, that the relationship between normative violence and impacts for 'being' did not seem as clear, robust nor helpful as it could be to assist providers in considering the negative impacts of their care and in encouraging them to reflect, rethink some of the taken for granted approaches and aims in their practice. This distinction I'm trying to make between norms and moralities is slippery: the normative and moral aspects of care are closely intertwined, and what comes to be accepted as moral is also normative (Castenada, 2006). To address these limitations in theorizing the affective and spiritual impacts of colonialism, I introduce and add the concept of moral violence<sup>20</sup> to normative violence. This recognizes that affective states such as fear, shame and anger, and spiritual harms like despair, social isolation and erosion of trust can be responses to moral violence

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<sup>20</sup> Castenada (2006) identified the moral violence of 'otherness' as the basis of violence in anthropologists' engagement with non-Western peoples, but the concept of moral violence has received little direct attention in critiques of colonization and health care. My conceptualization of moral violence in health care may imply a connection to the emerging anthropology of morals which examines the moralities of specific contexts (Fassin & Leze, 2014; Heintz, 2009). However, where the anthropology of morals seeks to avoid judging the moralities of specific contexts, my conceptualization of moral violence is situated in an understanding of historically and socially conditioned inequities, defined as preventable and unjust (Whitehead, 1992).

expressed at two levels. The first are the broader, *cumulative* moral harms enacted systemically through institutional structures, programs and practices that diminish, discount, or are indifferent to residents' personhood and right to self-determine. Although the colonial dynamics of institutions are not always or necessarily harmful, the potential for moral violence inheres in the commonalities and assemblages of disciplinary knowledges, rationalities, aims and interventions (Samson, 2003). Moral violence also inheres in social, political and material inequities which constrain people's choices and opportunities beyond bare existence. For Coast Salish scholar, Lee Maracle (2015), the imaginative and moral landscapes of stories act as 'maps' that inform ways of seeing and being in relation to others and what comes to matter. The systemic enactment of moral violence, I describe here, is informed by western cultural – colonial - 'maps of entitlement and belief' (Maracle, 2015, 70), which Maracle explains, 'in the hierarchy of things [produces and legitimizes] a social psychotic form of overstepping boundaries and violating those below' (p. 72). The second, and a constituent of cumulative impacts, is the way moral violence is enacted through projects of moral improvement. By drawing attention to the potential for *moral violence* in health care, I encourage providers to consider that the 'good' of care is always uncertain and contingent on residents' experiences. In this way, the concept of 'moral violence' aims to remind providers that it is often by acting on assumptions about the good of health care that harm is perpetuated.

### **2.3. Personhood, presence and relational process**

Cree writer and activist Edmund Metatawabin (2014) recalled that when he was introduced to settler ('wemistikoshiw') concepts of personhood, it left him feeling like, the world was full of lonely people, living in their tiny bubbles, and only reaching out when they had a need'. In contrast, he writes,

my Cree identity began with . . . [his wife, children, parents, siblings, aunts, and uncles]. It stretched back to my gookums [grandmothers] and moshums [grandfathers] through the ancestors, who guided us in times of trouble. And beyond them, it encompassed the Four-Leggeds [animals] and the Standing Ones [trees] and the earth itself and the River of Life. All my relations (parentheses added, Metatawabin with Shimo, 2014, p. 200).

Metatawabin's Cree perspective is reiterated by Indigenous scholars from various nations who locate Indigenous understandings of personhood in ongoing relationships

with communities, cultures, land and the cosmos (Alfred, 2009; Monture-Angus, 1999; Simpson, L., 2011). Based on her study of an Indigenous community in Australia, Heil (2006) argued that the scientifically (and statistically) defined beliefs of a 'healthy individual' were at odds with Aboriginal peoples' understandings of being a healthy individual which was tied to the quality of ongoing relationships with people. The importance of relationships superseded the biophysical needs of their bodies. The important shift needed in health care, Heil (2006) asserts, is not from the individual to the social context, but in the understanding of what it means to be a person: of being continually constituted by relationships with others.

In this study, I use the concept of personhood in three interacting ways. The first is the extent one *recognizes* another as a complex person, rather than seeing them as a member of a category. The second pertains to all that which constitutes one's individuality and the expressions of this. And the third pertains to the social dimensions, recognizing that personhood and relationality are not discrete concepts. Given my focus on health care relationships, this third point requires some additional discussion.

I view relationality is an inherent facet of personhood as without it, social life would not be possible. As discussed, for Indigenous Peoples relationality is often viewed as central to personhood and includes relationships with the land, other species and the spiritual realm. Simpson (2017) asserts that the 'hyperindividualism' of western society 'negates relationality' (p. 154), but this overstates and risks reinforcing the binary between Indigenous Peoples and settlers. While the diversity of settlers' ancestries preclude generalization, there is little question that in Euro-Western societies, relationality occupies a more limited role in understandings of personhood given the theoretical and philosophical emphasis on individualism, beliefs about the separation and superiority of humans over nature, and humans' ability to scientifically understand and control natural and social worlds. Providers placed various levels of emphasis on relationships and I argue that their personhood, specifically their desire and ability to relate to residents as persons, is often constrained by the same factors that constrain the personhood of residents.

In general, I observed that relationships were more prominent and extensive in the lives of many Indigenous residents. A few Indigenous residents reported having no connection with relatives, friends and keeping to themselves. However, when I came to

know two Indigenous residents who had made such comments, I observed that they regularly interacted with a range of people in their apartment buildings and within DTES, including contact with family members they had not previously told me about. In contrast, I knew numerous settler residents who reported and whom I observed had limited – if any – social contact with family or others in the DTES. In contrast to Indigenous residents, few settler residents had extensive social networks.

Although I recognized the centrality of relationships in Indigenous ways of thinking and being, I was slower to ‘see’ the importance of personhood, presence and process as *theoretical* precepts in many Indigenous scholars writing. Part of the challenge was the diversity or ‘theoretical promiscuity’ in Indigenous scholars’ writing (Simpson & Smith, 2014). Some scholars draw more significantly on non-Indigenous theorists (such as Coulthard, 2014a, 2014b), others mixed non-Indigenous with Indigenous forms of theorization (such as Teaiwa, 2014), some situated their work more fully within their traditions (such as, Simpson, L., 2011), and some shifted theoretical approaches to suit focus of their inquiry (such as Million, 2013 compared to Million, 2014). Without realizing it, I had been ‘looking’ for theory in the form of abstractions that were ‘distant’ from Indigenous scholars’ personal experiences, were recognizably different from theories I was familiar with, yet had some recognizable consistency among them. Indigenous theorization, like Indigenous Peoples were diverse and eclectic. The portal for ‘seeing’ Indigenous theories came, fittingly, through my interactions with residents. I had noticed how residents’ and providers’ understandings of respect and how they talked about ‘respect’ were often different. Where providers often talked about respect in the context of specific *practices* (such as ‘respecting’ resident’s choices), residents’ talked about respect as an *overall* experience of interactions that left them feeling recognized and accepted as a person and able to be themselves. For residents, feeling respected indexed providers’ way of being. I also noticed how residents, and more so Indigenous residents, often practiced respect by suspending criticism of others, by the importance many attached to interacting with others in ‘a good way’, and by not generalizing their views. As I reflected on the attributes of encounters where residents (Indigenous and settler alike) felt respected or described their spirits as having been ‘lifted’, I was able to ‘see’ the *theoretical* significance of personhood, presence and process in Indigenous scholars’ writings. As I discuss the importance of these in works by Indigenous scholars, I must emphasize first their concurrent recognition of and

respect for the diversity among Indigenous Peoples. In other words, the commonalities identified below should not be read as reinforcing contrasts between Indigenous and Western understandings of personhood, which are often framed in terms of individualism versus relationality (Conklin & Morgan, 1996).

Many Indigenous scholars have discussed personhood in the context of cultural values which, as I read across several scholars' work, reflected the importance of respect, humility, honesty, sharing, equality, kindness, responsibility and non-interference (Johnson, 2007; LaRocque, 2010; Maracle, 2015; Simpson, L., 2011; Wilson, 2008). Rather than prescriptions for behavior, subject to ongoing judgement and discipline, these values are discussed as guides for cultivating relationships and good feelings among others, and for strengthening community. While settler residents embraced some of these values in specific contexts or relationships, I noticed that these values were shared by many Indigenous residents.

Wilson (2008) explains that respect is predicated on humility in one's inability to know the experiences and relationships that influence another's behavior. This highlights the contingency and limitations of abstracted, scientific knowledge, of providers' expertise and therapeutic aims. Truth, according to Indigenous scholars, is not external to an individual but resides in the relationship one has with people, traditions, the land, and spirits (Simpson, L., 2011; Wilson, 2000). Respect is communicated through listening and speaking from one's experiences rather than giving advice, recognizing others' right to find their own meanings and to self-determine (Little Bear, 2000; Simpson, L., 2011). 'Criticizing or judging', Wilson (2008) explains, would imply 'I know more about someone else's work and the relationships that went into it than they do themselves' (p. 43). Within her Nishnaabeg traditions, Simpson (2017) explains that it would be 'unthinkable' for a leader to impose their will or agenda onto another. From Indigenous scholars' writings it becomes clear that when providers identify problems and goals or offer information and advice without adequate attention to residents' personhood, priorities and social realities, the delivery of 'care' may be experienced as an erasure, judgement and affront to their sense of being (Heil, 2006). It helps understand how an *experience* of disrespect can yield an embodied truth that is more influential than providers' words and practices.

The relational nature of personhood and respect emphasizes process: that how things are done (and, conversely, how they are not done) is a form of knowledge that registers in bodily responses, intuition and dreams (Simpson, L., 2011, 2017; Wilson, 2008). Dr. Evelyn Voyageur, a nurse and member of the Tsawataineuk First Nation, writes about the importance of working *with* people rather than *for* them. Working ‘with’ involves being present as a person, not only in one’s professional role. ‘I truly believe that people have to see us as a person, not just as a nurse,’ Voyageur is quoted as saying, because ‘they need to know that you are a human being who can relate to them at their level’ (in Drees, p. 201). ‘Being human’ includes the ability to laugh at oneself and to normalize rather than pathologize struggles, as well as embracing the inevitability of mistakes, doubts and shortcomings (Simpson, L., 2011; Wilson, 2008) as important sources of knowledge. An acknowledgement of messier aspects of being human is reflected in some scholars’ descriptions of cultural stories featuring the mythic characters (Graveline, 2004; Maracle, 2015). Leanne Simpson (2011), for example, talks about ‘Nanabush’ stories among Nishnaabeg peoples, in which Nanabush sometimes ‘assumes the role of ‘buffoon’ . . . in order to be an effective teacher’ (p. 73). Such stories accept the exigencies of life and highlight the value of being flexible. Lux (2007) argues that Indigenous Peoples’ ability to survive the famine and deaths between the 1880s–1890s was not the result of Western medicine, but their ability to adapt to the rapid changes associated with colonization, a point reiterated by Indigenous scholars (Graveline, 2004; Maracle, 2015; Simpson, L., 2011) and by many residents in this study. Together, Indigenous understandings of personhood and presence indicate that relationships predicated on vitality, connection and respect for self-determination – not pathology, distance, and governance – are the conduits for well-being: points which found resonance in resident’s experiences of health care. Against the contemporary challenges in Indigenous communities, some settlers might argue that Indigenous scholars offer an idealized, romantic view of Indigenous Peoples. Since Indigenous scholars acknowledge the devastating impacts of colonialism in their communities, I understand their writings as ‘calls’ to affirm Indigenous peoples strengths and the good in themselves, their communities, worldviews and traditions.

Many of the practices Indigenous scholars associate with the recognition of personhood, presence and process are also identified by settler scholars. For participants in Calabrese’s (2011) study, being ‘treated like a person’ meant physicians’

conveyed genuine concern, kept up with important events in patients' lives, and did not leave patients feeling rushed through visits. Carpenter-Song's (2011) study of medical encounters adds to this the importance of physicians' ability to listen and bear silences, their embodied sense what patients' feel during the encounter, and the recognition they can never fully know the patient. Katz and Shotter (1996) encouraged physicians to explore patients' understandings of their concerns and social realities. Adopting a respectful curiosity that seeks to understand patients' lives and social worlds enables providers to move beyond their one-sided medical perspective and allows patients to guide the interaction and reveal their pain 'in ways in which they are still healthy and vital beings' (Katz & Shotter, 1996, p. 920). Doing this helps equalize the power in health encounters. Human (2011) adds that local contexts and patients 'will always have more complexity than protocols will allow' (p. 236). The 'art' of medicine, in his view requires the readiness to deviate from protocols and take risks based on physicians' intuited sense of the patients' needs and local realities.

The interplay between colonialism and personhood becomes more concrete when considering how personhood is also shaped by social contexts. In Desjarlais' (2000) study of mentally ill men living in shelters, informants described the dehumanizing impacts of prolonged exposure to street life, but also found that shelter services and informants' relationships with staff could also be experienced as humanizing. For mentally ill people staying in shelters, fluid expressions of personhood were a political necessity to 'get things done' (Desjarlais, 2000, p. 485). The negative impacts of living on the margins of society for personhood do not preclude the acumen and agency required for survival.

My study supports Desjarlais' (2000) work by showing how social inequities influenced residents' personhood and interactions with providers. Extending his work, I contend that the structural and normative context of health care and providers' roles influences their ability to recognize residents' personhood. I found that generative expressions of providers' personhood were fundamental to cultivating supportive relationships. Coming to understand patients as persons situated in particular social contexts can help providers adapt care to the realities of patients, rather than trying to fit patients into the regimes of care.

## 2.4. Conclusion

This dissertation is premised on identifying and tracing continuities between colonialism in the past and present with my concept of 'colonial dynamics'. Although subsequent chapters examine how colonial dynamics are enacted in health care encounters, I have tried to underscore the *systemic dimensions* of colonialism by showing how the limitations and contradictions inherent in colonialism have also been observed in humanitarian initiatives. The writings of Indigenous scholars call attention to the importance of personhood, presence and process. I suggest that attention to personhood in health care encounters can help ameliorate the dynamics of colonialism and improve both the relevance and experience of care for residents.

## Chapter 3. Methods and ethics

*You can't decide to yourself, 'Oh, I'm going to collaborate with that group over there and boy are they lucky'... You have to instead really focus on establishing the basic groundwork of whatever it is you have to offer. And then you must wait for those relationships to unfold. (Reader in Younging, 2018, p. 34)*

### 3.1. What is collaborative research?

Cerwonka and Malkki (2007) write that anthropological research is less about rigid adherence to predetermined methods than cultivating a 'sensitivity' that is flexible and responsive to the issues and questions that emerge during fieldwork.

As discussed in the previous chapter, the colonial history of scientific research among Indigenous Peoples has been examined by critical scholars who trace how colonial assumptions are embedded in disciplinary knowledge, practice and research methodologies (Smith, 1999; Waldram, 2004; Wilson, 2008). Writing against this history, Maori scholar Linda Tuhiwai Smith (1999) argued for the use of 'decolonizing' research methodologies, which involve Indigenous people in all facets of research. This does not preclude the involvement of settler researchers but recognizes the need for *meaningful* collaboration between settlers and Indigenous Peoples when planning and undertaking research. According to Wilson (2008), collaborative methodologies express the centrality of relationship in Indigenous world views, ways of being, moralities and epistemologies. One of the primary roles of research, Wilson asserts, is to strengthen relationships between people and within communities. These ideas resonated with my affinity for collaborative work, discussed in Chapter 1, and with the relational priorities in my work as a nurse, but the full significance of collaboration didn't register for me until this thesis research was underway.

It was my intention to conduct a collaborative study with meticulous attention to a *process* that left all participants feeling valued and respected. I relied on institutional norms and guidelines regarding ethics and funding requirements, including compliance with the Tri-Council Policy Statement (TCPS2) on Ethical Conduct for Research Involving Humans (Government of Canada, 2014) and the Canadian Institute of Health

Research (CIHR) Guidelines for Health Research Involving Aboriginal People (n.d., 2013), which elaborated researchers' ethical accountabilities to 'Aboriginal communities'. My study received ethical approval from the Simon Fraser University Office of Research Ethics (ORE) and was supported by a research fellowship from CIHR.

The CIHR guidelines define collaborative research as adhering to principles of shared ownership, control, access and possession, or 'OCAP', as it's more commonly known. This study was collaborative in some respects, but I found that involving two groups of participants who live, work and interact in an unequal and interdependent relationship to each other presented limitations. The perspectives and priorities of each group were not necessarily congruent, and it was I – not participants – who determined the study's focus and methods, reviewed and analysed data, was responsible for ensuring analytic accountability, and research representations.

In my collaborative aspirations it is important to acknowledge where and how the ethics of collaboration were expressed. I selected a topic that both groups of participants saw as relevant and having the potential to strengthen health care encounters, and I placed great emphasis on understanding residents' realities and communicating their critiques. Consistent with Wilson's (2008) discussion of 'relational accountability', throughout fieldwork and the process of writing, I informally shared my evolving analysis with several residents and providers to check that it resonated with their experiences. As discussed in Chapter 9, I shared and discussed findings with participants at the end of the study and was open to including their responses in the final draft. I will also invite their participation in presentations or publications based on study findings beyond the PhD. I have tried to reflect and respect the humanity of participants by acknowledging their vitality and agency as they negotiated various forces that constrained their responses. As well, I have sought to recognize both the diversity and similarities in their beliefs, responses, experiences and desires. However, the asymmetries of power between researchers and residents coupled with many residents' feelings of exploitation encouraged me to keep residents' theoretical analyses at the forefront.

I often found it difficult to balance the asymmetries of power and the interdependent relationship of residents and providers with my ethical accountabilities to each group, my dual roles, and the way colonial dynamics shaped my own relationship with residents. By practicing reflexivity and listening to residents, I came to see how

colonial dynamics influenced my own thinking, practices and relationships. I share examples of these here and in subsequent chapters to show how I continue to grapple with my settler conditioning and positionality.

This chapter is organized in two parts. In the first part, I describe the nuts and bolts of my method: who was involved, the consent processes, data sources, and my approach to analysis. In the second part, I discuss the ethical complexities of my dual role as a nurse and anthropologist, the limitations of consent, and my accountabilities. Consideration of my position and power throughout the study was important in maintaining ethical accountability. I conclude this chapter with attention to the moral and affective dimensions of research relationships by questioning the ethics of endings.

## **3.2. Methods**

As mentioned in Chapter 1, during fieldwork I conducted two studies. The first was conducting an evaluation of the Vancouver Native Health Society (Native Health) 'Patient Self-Care Management Study' (PSMS). As mentioned in Chapter 1, in exchange for this work, Native Health provided me access to conduct my PhD research in the medical clinic<sup>21</sup> and the Drop-in Centre. I do not discuss the results or the process of the PSMS research in the dissertation, but it is important to mention because that was how I gained access to the research sites and it offered important background for my PhD research. The second study was my PhD research, which involved extensive participant observation, interviews, and documentary analysis. The methods used in the two studies were distinct in most respects but overlapped in that I conducted participant observation for both in physicians' offices-exam rooms and the Drop-in Centre, and numerous residents and providers participated in both studies.

### **3.2.1. Participants**

I review the general contours of my participant categories and summarize their involvement with various forms of data collection, before discussing the problematic aspects of these categories

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<sup>21</sup> To avoid confusion, I capitalize Clinic when referring to this setting at Native Health and use smaller case clinic when referring to the cluster of appointments, as in a morning or afternoon 'clinic', or when referring to other medical clinics in the area.

This study involved two groups of participants: residents and providers. Those I refer to as 'residents' lived with HIV and used illicit drugs, though a few reported having 'cleaned up' following many years of drug use. 'Providers' were employed in health services and included administrators, outreach workers, counsellors, nurses, physicians, social workers, medical office assistants, intake workers and pharmacists. A few providers also worked on a casual or part-time basis with other health services. During fieldwork, one Indigenous Elder started spending several hours at the Drop-in Centre every one to two weeks, interacting with residents and offering prayers. This Elder also oversaw an annual memorial ceremony on a nearby reserve for residents' who had passed away during the previous year. I was introduced to a second Indigenous Elder who worked with the Native Health diabetes program toward the end of fieldwork. At times I reference specific roles, such as physician or nurse, when differences in knowledge or status are important to the context.

### ***Residents***

As shown in Table 1, a total of 92 unique residents participated in study through interviews and / or by consenting to let me observe their medical encounters. Although I did not routinely ask residents their age I did happen to ask the youngest, who was in her 20s and I believe no one was older than 60 at the time of interviews. A total of 68 unique individuals participated in semi-structured and post-encounter interviews. This group of residents included 44 males, of whom 15 were Indigenous; 21 females, of whom 16 were Indigenous; and three people who identified as bisexual or transsexual (bi/transsexual), of whom two were Indigenous. The overall gender ratio of residents in the DTES is approximately 60% male to 40% female (City of Vancouver, 2013). In my study the gender ratio of unique individuals (excluding bi/transsexual residents) was slightly higher than this for male participants at approximately 68% and lower for female residents at 32%, which reflects the lower number of women accessing services in the Drop-in where participant-recruitment was concentrated.<sup>22</sup> The overall ratio of Indigenous people to settlers in the DTES is approximately 10% to 90% (City of Vancouver, 2013). In my sample the ratio of Indigenous residents to settler residents was approximately equal, which is consistent with the balance of Indigenous and settler clientele of Native Health (VNHS 2008/9 Annual Report).

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<sup>22</sup> Reliable demographic statistics for residents' accessing the Drop-in Centre were not available.

During the first three months of fieldwork, I recruited six residents for more involved and ongoing participation during the first year of fieldwork. Closer relationships with these individuals enabled me to gain a fuller understanding of residents' everyday lives over time and to see how their personal histories and changes in their health and social realities impacted their relationships with providers. These residents consented to being interviewed every two to three months, granted me access to their records at the Drop-in Centre and Clinic for the first year of fieldwork, and participated in a number of other activities. I selected these residents to

obtain a balance of genders, ethnicities, and diversity in the number of years they had lived with HIV. As my focus was initially on HIV, I placed emphasis on recruiting residents who had declined in their health or were taking ARVs sporadically. All women in this core group were Indigenous, reflecting the smaller number of settler women who visited the Drop-in Centre when I began fieldwork. While only one man in this core group was Indigenous, as fieldwork progressed I met and had regular involvement with four more Indigenous men and one Indigenous woman through serial interviews and other activities. In addition to interviews and observations within the Clinic, field data was derived from participant observation of and field notes on activities such as walking tours; 'hanging out' in parks and on the street; visiting residents in their homes and in hospital; accompanying them to appointments, on bottle-collection routes, and in visits with friends or family; attending films and special events and taking trips outside the area.

**Table 1: Number of Resident-respondents by Form of Participation**

Number of Respondents		Form of Participation	Number of Interviews and / or Observations
Per Form	Unique Individuals		
56	56	Semi-structured interviews	163
18*	12	Observation of medical encounter <i>and</i> post-observation interview	21
24	24	Observation of medical encounter alone	28
<b>Total 98</b>	<b>Total 92</b>	<b>Total Interviews (163 + 21) = 184</b>	
		<b>Total Clinical Observations (21 + 28) = 49</b>	

\*Note: Six residents who were observed in medical interactions and participated in post-observation interviews, also participated in semi-structured interviews.

For an additional 24 residents, participation was limited to observations of their medical interactions. I observed 49 medical interactions and conducted open-ended

interviews with 18 residents following observations of 21 medical encounters. I observed two additional medical interactions but excluded these from analysis on learning the residents were not HIV positive. Together, the total number of unique individuals who participated in interviews and/or were observed in medical interactions was 92. Many were interviewed and observed more than once.

### **Providers**

As shown in Table 2, a total of 73 providers, representing two groups, were involved in this study. The primary group of 48 providers were employed at Native Health and worked in administration, the Clinic, the Drop-in Centre and a diabetes project. Of these providers, 31 were women and 17 were men, and they ranged in age between early-20s and 60s. A total of seven Native Health providers were Indigenous. The Clinic reception was staffed by a mix of intake workers and medical office assistants who filled a variety of full-time and part-time roles. Twelve clinic physicians consented to participate, including four with an emphasis in HIV care, five generalists, one specialist in HIV care, and two family-practice residents. Eight of these physicians were regular part-time employees, two were full-time during their family practice residency, one (a medical specialist) worked one clinic per month, and one physician worked one morning per week as part of a contract through the Drop-in Centre. This last physician also worked at a health authority clinic nearby.

**Table 2: Number of Provider-respondents by Agency and Form of Participation**

Number of Respondents	Provider Group	Number of Providers by Form of Participation		
		Interviews and Observations	Interviews Only	Observations Only
48	Native Health	26		22
25	Other Agencies		25	n/a
<b>Total = 73</b>				

Note: The total number of observations includes those which were followed by a post-encounter interview

Of these 48 providers, as shown in Table 3 on page 84, a total of 26 representing the Clinic, the Drop-in Centre and the administration participated in a total of 46 semi-structured interviews. Of those who participated in interviews, 11 were male, 15 were female; seven were Indigenous. In addition to interviewing providers and observing providers in each site, participant observation was conducted during outreach activities,

staff meetings, and meetings with external parties; in addition, I joined demonstrations, agency-wide functions, conferences and social functions.

The second group of 25 providers worked (previously or presently) with other agencies in the DTES, in St. Paul's Hospital where many residents received emergency care or were hospitalized on a special ward for people with HIV, or in other health care settings outside of the DTES. Using a 'snowball sampling' approach, I asked residents and providers at Native Health to identify providers they thought would have a unique or important perspective on the development of HIV services. This generated a list of providers with experiences in outreach, pharmacy, health research, health administration, and multiple nursing roles (street nursing, home-care nursing, acute care, emergency services, HIV education, and specialized HIV and addiction services). Providers in the second group offered insight into the changing landscape of health and HIV services in the DTES from the beginning of the HIV epidemic. Of the 25 people in this group of providers, 17 were men and eight were women, and only one person reported Indigenous ancestry. Twenty participants had past/present involvement with health services (14 in nursing, four in pharmacy, one in medicine and one in social work). The remaining five people had past/present engagement in faith-based services, health research, advocacy and contract work in Indigenous health. This group of 25 providers participated in a total of 36 semi-structured interviews.

### ***Questioning categories***

As I learned more about participants' lives and various roles, I saw that the categories of 'residents' and 'providers' were problematic. My participant categories did not account for the social positions situated in the spaces between. For example, Native Health provided some residents with a financial stipend for their work in 'voluntary' roles in the Drop-in Centre or in special initiatives, such as the role of 'peer coaches' with the agency's Patient Self-care Management study. In addition to a source of income, these positions increased residents' status among counterparts and with several providers, and in turn, their access to other resources in limited supply. However, in contrast to providers who received regular wages, had a level of job security and more social status and power than residents, the 'in-between roles' that residents occupied were short-term, without benefits or avenues for advancement. Inequities were structurally reinforced by welfare regulations that stipulated if residents earned more than \$200 per

month it would be deducted from their benefits. My category of 'provider' also failed to account for many residents who assumed unpaid roles as caregivers for partners, friends, neighbours and community members in their everyday lives. I learned that these informal networks of care were often the 'first-line' of care in residents' lives, yet these care-giving roles were often invisible to providers. In the context of medical encounters, residents were positioned as patients, but providers could also become patients. However, providers' roles as patients were rendered invisible by occurring in the context of their personal lives, which were beyond the scope of this study.

My participant categories of providers and residents did not account for similarities in some participants' levels of educational attainment, material status, histories of poverty, abuse, discrimination and involvement with systems of authority. Two residents with post-secondary diplomas, for example, had previously worked in health care. Several providers had backgrounds in business, construction or other non-service fields, as did several residents. A few residents and providers reported alternating periods of employment, unemployment, and struggles with alcohol or drug use at various times of their lives. Several providers had friends and family members engaged in street life, and numerous residents had friends and family members who were financially secure, had stable housing and, in a few cases, were employed as providers. A few providers told me that their work roles offered the primary source of social contact, just as some residents found the Drop-in Centre their primary source of social contact.

The term provider elided occupational and social hierarchies among providers as evidenced in the gradients of remuneration and status between intake workers, nurses, and physicians. Similarly, 'provider' did not reflect how the hierarchies between staff interacted with the hierarchies between programs. The diversity of social and health services in the Drop-in Centre, and the diverse backgrounds of staff made it difficult to classify and contributed to it having lower status than clinical services. Yet, the Coordinator of the Drop-in, a nurse, had higher status than reception staff in the Clinic and leveraged this at times to facilitate some residents' access to medical care.

The term 'resident' also glossed important social distinctions in the organization and networks of their everyday lives. Residents tended to socialize with peers who used the same drugs and gathered or lived in the same place, leading one woman to

characterize the north and south sides of Hastings Street as distinct social worlds. Moving from a hotel on the north side of Hastings to a hotel on the south side, she found herself in an unfriendly social milieu. She soon returned to the other side of the street.

The only consistent difference between residents and providers, as groups, was that at the time I conducted fieldwork residents were engaged in street life, dependent on social services, and had extensive present or recent use of illicit drugs, and providers were economically independent as a result of employment in health services and commuted in for work. While all residents who participated in this study were HIV positive, I did not ask providers about their HIV status, so do not know how HIV infection differentiated the groups.

The instabilities of residents' lives stand in contrast to the fact that the social networks I became acquainted with between 2009 and 2011 have remained relatively unchanged, with the exception of those who have died or moved away. Relative to residents' lives, services in the DTES tend to be viewed as sites of stability but in programs and staff there have also been many changes. Although most of the providers who worked in the Clinic during fieldwork still remain, there are many new physicians and, as mentioned in Chapter 1, there are changes on the horizon as some physicians will leave in Fall 2018 to open an independent Clinic. Of the 19 providers who worked in the Drop-in Centre when I conducted the study, only two staff members remain. Three different people have filled the Coordinator role *since* fieldwork and the program's future is now uncertain.

### **3.2.2. Consent**

My PhD study, as mentioned, received ethical approval from the SFU Office of Research Ethics and the executive director of Native Health. And, as noted earlier, I conducted another smaller study for Native Health which evaluated the impact of coaching on patient self-management study (PSMS) as a condition to gaining access to the clinic. To reduce the chance of residents confusing my PhD and PSMS research roles, and of providers' confusing my status as researcher with my status as a nurse, the Letter of Agreement with Vancouver Native Health Society stipulated that I would not provide nursing care (Appendix A). Providers accepted this with grace and there were few instances when I was asked to assume a nursing role. To promote clarity with my

PhD and PSMS work, before consents were signed I met with all providers in the Drop-in Centre, the Clinic and the PSMS study (including resident coaches) to explain my respective research roles.

All providers at Native Health signed a written consent form granting me permission to conduct interviews and participant observation of their interactions with colleagues and residents, and of their meetings and individual interactions with residents (pending residents' verbal consent). A passive consent process was used to inform residents about my observations in the Clinic's reception area and the Drop-in Centre. This included a poster with my picture and an explanation of the study that was taped to the wall in both reception areas as well as to the bulletin board in the Drop-in Centre.

On the advice of the Clinic manager, I followed the same process previous researchers had used to elicit residents' consent to observe their medical encounters. This process involved intake workers whose role it was to assign medical appointments. If the intake worker knew the resident was HIV positive, the resident was shown a short, written explanation of the study that asked if they would be willing to let me observe their medical visit. If the intake person sensed hesitation they offered to read the statement. I was seated in the reception area, so once the intake worker gestured to me that the individual had consented, I quietly introduced myself, asked if they had any questions and reiterated they could ask me to leave at any point during the doctors' visit.

To promote residents' comfort, I encouraged providers to ask me to leave if they sensed a resident was becoming uncomfortable with my presence. I also left if I picked up on nonverbal cues given by the resident or the provider or sensed the resident would be more comfortable discussing the matter alone with a provider. Before group meetings I asked facilitators if they were comfortable with my presence. If I was unable to obtain consent before meetings I did not participate. If visitors were in attendance at such meetings I briefly explained my project, the purpose of observations and elicited their verbal consent to let me observe.

A signed written consent form was obtained for all residents and all providers outside the area who participated in interviews (see Appendix B). To promote privacy and place participants at ease, all were invited to meet off-site in a local coffee shop or restaurant of their choice for interviews. Residents also received an additional \$20

honorarium. The honoraria increased to \$25 toward the end of the first year as my moral and ethical unease with my role in the local research industry increased. Throughout fieldwork when interviews were much longer than an hour, I increased the honoraria by \$5 to \$10. When shadowing residents for specific activities, honoraria were calculated at \$15/hour, which was consistent with the hourly rate resident-coaches in the patient self-management study received. Following other studies conducted in the clinic, honoraria were not given for clinical observations. Following clinical visits, if residents were not rushed and seemed open to contact, I invited them to a meal to convey appreciation. To thank the six residents who had ongoing involvement throughout the study, each was invited to choose a special activity to conclude our time together. One resident referred to this as the 'graduation' and the activities they selected included visiting extended family outside Vancouver, a day at the Pacific National Exhibition and day-trips to two lakes in the lower mainland.

### **3.2.3. Data collection**

#### ***Participant observation***

The first three months of fieldwork concentrated in the Drop-in Centre, which allowed me to interact informally with residents. The fluidity of interactions there, and the fact providers did not take breaks, made participant observation the primary method in this setting. I observed and participated in resident-provider interactions across the spectrum of activities and special events, including meal services, preparation and distribution of ARVs, nursing services, the weekly food bank, weekly groups, special events and outreach. I visited with residents waiting on the sidewalk before the doors opened and in the smoking area by the back door. To understand the realities of providers in the Drop-in Centre, I observed the administration of ARVs, attended staff meetings, and joined informal conversations in the nursing office and occasional 'debriefing' sessions after work. In addition to observing nursing care, I joined providers in attending rallies, parades, presentations and discussions of program services with external groups. I also attended the annual day-long ceremony to commemorate residents who had passed away the previous year (colloquially described as 'the Burning') and the opening of the Indigenous Elder's Church on a nearby reserve.

Observation in the Clinic reception included waiting with residents for medical visits and attending one staff meeting. Most observations occurred during weekday mornings and afternoon clinics. I attended two evening clinics and had incidental contact with Clinic staff on weekends and when I retreated to the relative, ordered calm of this setting to write field notes.

With the clinic coordinator's concern about research fatigue in the Clinic, I confined observations of clinical interactions to a four-month period and then allowed several months before inviting physicians for interviews. I observed a total of 49 clinical encounters, involving eight physicians and 43 residents. Some residents were observed more than once, which enabled me to explore continuities and discontinuities across multiple visits. The number of clinical encounters observed with individual physicians ranged from one to 13 with an average of six. To gain insight into concerns of everyday medical practice, I attended several medical staff meetings and reviewed all minutes from such meetings that took place in the first year of fieldwork. There were few opportunities for informal interactions with physicians so insight into physicians' realities and perspectives were derived primarily through successive interviews.

Outside of Native Health, I spent time with residents in their homes, collecting redeemable bottles, making the rounds of agencies to get meals or other services, and hanging out in local parks and on the 100 block of Hastings Street. Eight residents provided guided walking tours of the area at different times of the day and week. One tour began at midnight on the day that welfare cheques were issued and enabled me to observe a range of activities associated with the monthly influx of money. I also joined local demonstrations; observed residents buying, selling and using drugs; accompanied one resident to a court appearance and another to First Nations and Inuit Health Branch to apply for his annual Treaty money; and joined two others in their efforts to locate housing. Several residents introduced me to family members within and outside the area. To broaden my understanding of residents' experiences with health care services, I accompanied residents to various appointments (optical, blood work and X-rays), to emergency rooms at two hospitals, and I visited many while they were hospitalized. To elicit residents' responses to official representations of the DTES, I invited several to join

me for the screening of a documentary about the area.<sup>23</sup> As Vancouver was the site of the 2010 Winter Olympics, one resident joined me in attending a panel presentation on the local impacts of the Olympics and visiting an Olympics information kiosk about the DTES.

### ***Field notes***

Given the intensive surveillance of residents' lives, I avoided taking notes when informally interacting with residents. In this way, I sought to reduce the likelihood of residents feeling objectified as data and arousing suspicion about my intentions or activities. I also avoided asking too many questions during informal interactions lest residents feel I was exploiting their goodwill (Tomaselli, 2003). One resident said this practice conveyed respect, but it left another resident thinking informal interactions were 'off the record'. During interviews I limited jottings to the words or phrases necessary to facilitate later recall. More detailed notes were taken following interviews and clinical observations, during lulls in interactions, and when taking the bus to and from the DTES. Each night I entered field notes into password-protected files on my computer.

### ***Interviews***

As shown in Table 3, a total of 266 open-ended and semi-structured interviews were conducted with a total of 119 individual participants in the study. The large number of interviews is not fully explained by having reached 'saturation' with the data. Even when I had acquired a reasonable understanding of residents' everyday lives and their experiences of health care, I found additional interviews often yielded important and new insights. A desire for comprehensiveness was the impetus for numerous interviews. During fieldwork I also decided to include some oral history of the epidemic with my historical chapter which led to many additional interviews. A subtext to the data I collected, were my insecurities in having moved from nursing to conduct doctoral research in anthropology. The second year of fieldwork, as I gained confidence in my data, the interviews naturally tapered off.

Interviews ranged from 30 minutes to 2.5 hours in duration. Most interviews were audio-recorded and all but 13 were personally transcribed. During clinical observations, I

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<sup>23</sup> The film was *Fix: The Story of an Addicted City* (Wild & Carson, 2002). I noted residents' responses during the film and subsequently interviewed each resident to elicit their thoughts and reactions.

took notes of each party's verbal and non-verbal responses and elaborated upon these after each observation. When residents were uncomfortable being recorded, I took brief notes during the interview, expanded these immediately afterward, and again when entering notes into the computer that night. Over time, all residents who were interviewed more than once agreed to be recorded. Details noted in early interviews were often subsequently reiterated. Details that were not repeated in audio-recorded interviews usually pertained to their early lives, experiences with work and raising families and romantic relationships. All participants had the option of reviewing copies of their transcripts upon request, but I did not permit anyone to review my field notes. Several providers and two residents requested their transcripts, and I amended transcripts for those who requested copies.

Excluding post-observation interviews, a total of 56 residents participated in 163 semi-structured interviews. Serial interviews with the core six residents began with questions exploring the residents' background (pending their receptivity) and eventually included other topics such as health (with emphasis on understandings of and experiences of HIV care), family, interests, social and financial matters, drug use and personal concerns. I also interviewed many more residents who, through informal interactions, I identified as being able to offer additional insights on the everyday life before and through the early HIV epidemic, drug-dealing and use, relationships, sex work, efforts to obtain housing, adjustment following prison terms, and panhandling practices. To protect privacy, I usually asked residents to step outside Native Health before I approached them for interviews. When residents approached me for interview-work, I explained interviews were 'by invitation only'.

Before each interview I prepared a list of semi-structured and open-ended questions that addressed current areas of inquiry and questions that had arisen from participant observation. These questions helped start the interview, but I tried to remain flexible and follow other topics that surfaced spontaneously. As fieldwork progressed, interviews became more fluid and included questions about my emerging analysis. I noted residents' gender, approximate age and ethnicity, but given the scrutiny of their lives, I only asked for demographic information when it was pertinent to the content of the interview.

Eighteen residents participated in 21 open-ended interviews following observations of their clinical encounters. I had not met 12 individuals prior to observations of their clinical encounters. The remaining six residents were also among the 56 individuals interviewed about their broader experiences in the DTES. To promote recall, most interviews occurred within several hours of the visit, though two were conducted the following day. Eight residents

approached for interviews declined on the basis they were too busy, not interested or were unavailable within a day of the visit. The decision to approach residents was based on the nature of concerns discussed during the visit and my sense of residents' receptivity. I didn't approach residents for post-observation interviews if the clinical visit was limited to renewing a prescription, if residents made no verbal or eye contact with me, or if they seemed agitated or rushed. I tried to avoid asking for residents for interviews while they were in the physician's office, but as they often left in haste this wasn't always possible. Post-observation interviews focused on how residents felt the visit had gone, explored their understanding of medical information that had been discussed, inquired about any outstanding concerns or responses they had to the visit, and addressed questions arising from my observation.<sup>24</sup>

**Table 3: PhD Interviews by Respondent Category and Number of Interviews**

Respondent Category	Number of Respondents		Number of Interviews
	Per category	Unique Individuals	
Resident Interviews	56	56	163
Resident Post-Observation Interviews	18*	12	21
Providers from Native Health	26	26	46
Providers from other Agencies	25	25	36
<b>Total</b>	<b>125</b>	<b>119</b>	<b>266</b>

Note: Six individuals who participated in post-observation interviews were also among the 56 interviewed about their broader experiences in the DTES

Twenty-six providers at Native Health participated in a total of 46 interviews. Interviews with providers in the Drop-in Centre concentrated on selected areas of expertise, program operation or the broader context for ARV services<sup>1995</sup> and funding. Most of the interviews with Clinic staff and physicians occurred during lunch hours,

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<sup>24</sup> It was not possible to determine in advance which visits would be appropriate for post-encounter interviews. A seemingly straight forward visit for a prescription renewal could end up addressing several topics. I thus observed many visits which were not appropriate for post-encounter interviews.

which meant interviews were usually rushed and followed prepared questions more closely. Interviews with reception staff concentrated on understanding the context and nature of their work and the beliefs and rationalities that informed their responses to residents. All Native Health-employed physicians involved in HIV care were invited to participate in serial interviews to help me understand their realities and perspectives about medical care. A total of six physicians (three male and three female) participated in one interview each. I was only able to observe one female physician's clinical practice in detail so was unable to compare the influence of physicians' gender between interview responses and clinical practices. Serial interviews with physicians began with general questions about their background and practice in the DTES and then moved into specific areas of practice such as social-health concerns, addiction, pain-management, and whether or how they observed differences between Indigenous and settler residents. The content of physician interviews shifted as my understanding of medical cognition, rationalities and clinical realities deepened. Twenty-five providers who were involved with past/present HIV services and were not employed by Native Health participated in 36 interviews. These interviews explored the history of their involvement in the DTES, their initial impressions of residents and the area, and developments in HIV services with attention to identifying major 'shifting points'.

### ***Additional data sources***

I also analysed Native Health annual reports, proposals for an early HIV partnership between St. Paul's Hospital and Native Health, and newspaper clippings from *The Vancouver Sun*, *The Province* and *The Globe and Mail*, found in the St. Paul's Hospital archive. These clippings were compiled by an administrator with a prominent role in responding to the early HIV epidemic in Vancouver and spanned the years from the mid-1980s to early 2000s. Although the clippings were not the product of a systematic review they reflected events that held some significance to the administrator. The archive helped identify shifts, tensions and debates through the peak years of the HIV/AIDS epidemic at the local, regional and provincial level and offered an indicator of changing societal responses to the DTES from before ARVs were developed until the time ARVs were publically funded and widely available. I also conducted an analysis of 253 abstracts of studies that had been conducted by the BC Centre for Excellence in HIV (BC-CfE) in the DTES. The studies ranged from 1998 to December 5, 2013.

Abstracts were posted on the BC-CfE website when I conducted the analysis in 2014 but have since been removed.

My analysis of abstracts sought to obtain a rough indicator of the professional capital associated with the biomedical research industry in the DTES. The review considered the total number of authors, how often they were cited, their institutional affiliation and the specific focus of each study.

### **3.2.4. Analysis**

*Stories go in circles. They don't go in straight lines. It helps if you listen in circles because there are stories inside and between stories, and finding your way through them is as easy and as hard as finding your way home. Part of finding is getting lost, and when you are lost you start to open up and listen. (Tafoya, 1995, as cited in Wilson, 2008, p. 6)*

The recursive, spiralling nature of ethnographic analysis is well recognized but when I started analysis I instinctively reached for 'systematic' approach only to find this at odds with my relationship to the data. I borrowed suggestions from books, but analysis was an embodied, 'improvisational practice' defined by intuition, trial, error, and a lot of writing (Bird, 2005; Cerwonka & Malkki, 2007).

A preliminary form of analysis was ongoing with fieldwork. Entering field notes into the computer each night evoked additional details, images, impressions and bodily sensations. I noted differences in meanings, values, beliefs and understandings of social situations and behaviors. I also paid attention to arguments, misunderstandings and rumours and sought to understand how observations were shaped by asymmetries in power and respective social realities. My questions evolved with my understanding. For example, when walking down the sidewalk with male residents, several made a point to be on the side closest to traffic. Inquiring about this, one man told me it was a means to convey respect for women. Another explained that walking on the side closest to traffic meant that the woman was not available for solicitation, thus implying that if male residents were walking with a woman, she was likely to be a sex worker. My inquiries opened the door to subsequent conversations with male residents about what it meant to 'be a man', the importance of masculinity in street life, and the impacts of interactions with social and health services on their masculinity. It also opened the door to exploring

about what it meant to be a woman in the context of street life, and in relationships with partners, siblings and children.

During fieldwork I developed a system for organizing field notes. I grouped field notes in computer files of approximately 100 pages each. When entering notes into the computer I created numerous sub-headings according to events, activities, sites and interactions with specific individuals – a practice that helped navigate the corpus of notes during analysis. Following fieldwork, but before coding data, I read all interviews and 1,500 pages of typed field notes. I then re-read and thematically coded all interviews and reviewed the first 1,100 pages of field notes in entirety three times.

Daunted by the volume of data and that thinking ‘good’ analysis required a more systematic approach, I turned to N-Vivo to help manage data. However, after two months coding interviews and field notes with N-Vivo, I abandoned it. When the data was fractured into countless codes I lost sight of the person, the inter-subjective and social context of our interactions, and the relationships between interactions, observations and the entire living body of data. I then turned to methodological texts that talked about focused coding and memos, but this also didn’t make sense (see Emerson et al., 1995; LeCompte & Schensul, 2013; O’Reilly, 2005) given my experience with N-Vivo. The labour and time involved in line-by-line coding was ill-suited to the volume of my data, and I couldn’t see how a line-by-line analysis would enable me to make broader connections. Nor could I see how generating another level of documentation in memos would help since I couldn’t manage the existing volume of data.

I returned to transcripts, divided them into sets, and reviewed each set in detail. For example, transcripts from interviews with physicians comprised one set, the transcripts from post-observation interviews another, and so on. Within sets, I grouped interviews and relevant field notes for each participant and analyzed them as a distinct subset. This allowed me to recall the immediacy of each interview by envisioning the setting and the feelings evoked by residents’ responses in moments of hesitation, emotions associated with certain topics, as well the unexpected insights, wit and sense of rapport between us. Analysis was a sensory and affective process: I needed to handle the transcripts and field notes, to see my notes scribbled in margins and the images the notes called forth, and to feel the bodily sensations and emotions evoked by the data (Bird, 2005; Brooks, 2010). In addition to writing notes in transcripts and in field notes, I

placed sticky 'flags' on pages with salient material. In later stages of analysis I alternated between reviewing the flagged pages and reviewing the transcripts in their entirety.

I read transcripts and pertinent field notes within each set several times and in several successions. Successive reviews opened into wider fields of analytic consideration. Analysis roughly followed a pattern: initial reviews concentrated on highlighting statements of interest, thematic coding and adding my reflections. I then identified idioms, continuities, contradictions and disjunctures within and across each set of data. I had limited information about providers' backgrounds, but with residents I tried to consider how stories of their past/present experiences influenced their beliefs, interpretations and responses. I gave attention to examining the meanings within and between their social realities. What did data say about the values, beliefs, norms and logics within respective realities? Where and how did meanings between realities of the street and health services overlap, clash and diverge? How did asymmetries in power and respective social realities shape the interpretive flows? When I noted points of agreement, tension, judgements and misunderstanding, I considered the beliefs and rationalities that underlay these. I also considered how social realities shaped beliefs and practices and then how the other party interpreted these practices. I looked for exceptions and nuances to prevailing meanings. And consistent with Indigenous methodologies (Smith, 1999; Wilson, 2008), I considered where and how participants' personhood, presence, self-learning, and relational process were expressed.

Having 'embodied' the data, I then needed to release it in the process of analysis (Bird, 2005; Brooks, 2010). This unfolded in two concurrent processes. The first was creating countless mind-maps to explore how various ideas and themes fit together. The second was writing various 'dummy drafts' in conjunction with my ongoing review of data. 'Writing wide', without worrying about the organization or content, each iteration raised new questions, drew new connections, and deepened my awareness of what was important and why. In a spiralling fashion, as the data was unfurled in text, the trajectory for the dissertation emerged.

### **3.3. Ethics**

The ethical considerations of this study posed significant challenges, which I discuss in the following sections. I begin by discussing ethical complexities associated

with my dual role as nurse and anthropologist and the limitations of consent. The next section considers my ethical accountabilities to both sets of participants in analysis. The final section reflects the ways inequities were reproduced in my research practices and considers the weight of health research for residents.

### **3.3.1. Ethical complexities**

#### ***Nurse-anthropologist***

The CIHR fellowship I received to conduct this research is awarded to health professionals completing their PhD and is contingent on maintaining an active nursing registration. This meant I was accountable to ethical codes governing anthropology *and* nursing. I referred to the American Association of Anthropology's Revised Code of Ethics (2011) and the Canadian Nurses Association Code of Professional Nursing Ethics. Literature on 'professional boundaries' acknowledges 'dual' relationships in the context of having a professional role augmented by personal roles in the community (Kagle & Giebelhausen, 1994; Sawyer & Prescott, 2011). In my case, the ethical codes for anthropology and nursing both recognize asymmetries in power and emphasized the need to avoid harm and protect vulnerable individuals. There were also important differences. Nursing codes for relationships were declarative and, because of the tie to licensure, always carried an implicit threat of sanction. The tone of these statements generated much angst for me because accepted anthropological practices often transgressed those for nursing. For example, the College of Registered Nurses of British Columbia (CRNBC) practice standards in *Boundaries in the Nurse-Client Relationship* (2018) states, 'Nurses do not enter into a friendship or romantic relationship with clients.' In anthropology, friendships with informants are common and even romantic ties aren't unusual (Fricke, 2006; Grindal, 2011; Lassiter, 2005; Newton, 1993). CRNBC (2018) differentiated professional from personal relationships along several indicators:

Professional relationships are 'time-limited for the length of the client's need for nursing care', where personal relationships 'may last a lifetime'. . . . Professional relationships are goal-directed as the 'nurse provides care within a defined role and follows an established plan of care', where personal relationships are 'pleasure and interest directed'.

But in anthropology, relationships formed during fieldwork are not time-limited, but may last for many years or a lifetime. And while fieldwork relationships were 'goal-directed', in

terms of generating data for my PhD, they were also pleasurable and could be interest-directed for residents and for me.

The CRNBC (2018) practice standards for professional boundaries state ‘Nurses use professional judgement to determine the appropriate boundaries of a therapeutic relationship with each client’ and that ‘The nurse - not the client - is always responsible for establishing and maintaining boundaries’, but anthropologists are dependent on participants’ willingness to work with us. Anthropologists’ dependence on host communities and respondents can mediate asymmetries in relationships and it can also make us vulnerable. This vulnerability is not, of course, equivalent to that of research participants, but it does remind us that power is not monolithic. Fieldwork causes anthropologists to question assumptions, and among the many questions that surfaced in this project were what differentiated research from service, since many research projects, also offer services. I didn’t see myself offering a service, but several residents said what I offered was precisely ‘the kind’ of health service they wanted: someone who invited them out for coffee to talk about things going on in their lives. The therapeutic benefits of ethnographic research as noted by residents were also observed by Robertson and Culhane (2005) and Elliott (2007). Close personal ties are often a feature of research conducted in/with Aboriginal communities (Dana-Sacco, 2010; de Leeuw et al., 2012; Robertson, 2012). Ethical codes for anthropologists, in contrast to those for nurses, recognize that each context and each ethnographic project is unique. Close relationships with participants are common, expected, and desired features of fieldwork. Consequently, the ethical codes for anthropology offer guidance rather than rules for research relationships, recognizing that the nature of research relationship are difficult to anticipate, and that ethical conduct is situated in the particularities of each context and relationship.<sup>25</sup>

Providers identified me as a nurse and maintaining professional respect was important for access and rapport throughout fieldwork, and for professional opportunities beyond the PhD. As relationships with a few residents evolved into friendships, I began feeling uneasy and contacted a practice consultant at CRNBC. When I described my

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<sup>25</sup> The CSA (2011) states: ‘Members *should* be aware that such inequalities of power pertain not only in coercive but also in consensual relationships. They *should take care* that *personal . . . relationships* entered into at work on a consensual or reciprocal basis do not exploit those inequalities of power, and do not disadvantage or unfairly advantage the less powerful’ (Emphasis added, p. 8).

research relationships, the impression that I had ‘crossed’ a line was reflected in her surprised response, ‘And this is OK with your supervisor?’ (Field Notes, n. d., 2010). When I reviewed CRNBC *Boundaries in the Nurse-Client Relationship* (2013), emotional and social engagements with patients were described as ‘abuse’. The guidelines for professional boundaries have since been revised with a softening of the language, but the disciplinary tone of the previous version was reminiscent of the authoritarianism of my basic nursing education, which cultivated a guardedness with nursing authorities that has never left me. Considering that the relationships I had as an anthropologist could potentially lead to professional discipline as a nurse caused growing anxiety as some relationships with residents became more personal.

There is an ethical asymmetry in how nurse-researcher relationships are viewed with patient-subjects, compared to those with provider-subjects. No one blinked when I, as a researcher, became friends with providers. A few times providers and I went for dinner, attended events or talked about our lives. Similar activities with residents invoked different assumptions. Without thinking, I refrained from drinking with residents where I would readily join providers for a beer. It was partly pragmatic: I didn’t want to create expectations among residents. Through most of fieldwork I also carried a tacit belief that to drink with residents was somehow unprofessional – a belief supported by the prominence of addiction and ‘therapeutic boundary’ discourses in health services. Late in fieldwork, I read about ethnographers who drank or used drugs with informants. It allowed me to recognize constraints on my relationships with residents that I hadn’t, until then, been aware of (Adler & Adler, 2012; Bourgeois, 2003), drawing attention to how my professional socialization influenced my research practice. When I finally did enjoy a beer with a resident she commented on how much it meant to her. I would have refrained if she was trying to stay sober, but she had no intention of doing so.

### ***Limitations of consent***

Residents’ poverty and dependence on services precluded the idea of ‘freely given consent’, but residents were not passive subjects. Many brought their own ethical review processes and ethical criteria to the study. For example, numerous residents said their decision to participate was based on a ‘gut’ feeling about my intentions and/or on observations of how my commitments ‘lived’ in interactions with others. One man ‘vetted’ me by talking with a friend before agreeing to an interview. The consent form

encouraged residents to express any concerns or complaints about the study to the coordinator of the Drop-in Centre or the director of the SFU Office of Research. I never heard that anyone (providers or residents) formally expressed concerns about my conduct, but I came to understand that institutional attempts to protect residents were at odds with street ethics that sanctioned 'ratting someone out' to authorities. If residents didn't want to be interviewed they brushed me off or avoided me.

I tried to mediate the imbalance of power when obtaining residents' consent by being attentive to signs of unease during the formal consent process, before and during each interview, and with other interactions in the community. As mentioned, in interviews, if I sensed a resident's hesitation to being recorded I took notes instead. If I sensed discomfort or agitation, I reminded residents they were free to pass on any question and asked if they preferred to skip that question. I prefaced sensitive topics with a reminder that residents may not want to answer the next question. One resident said the practice helped him avoid feeling caught off guard. When sensing fatigue, hesitation or emotional discomfort, I asked if residents preferred to discuss something else or if they were getting tired. When I was uncertain about residents' comfort level, I shared the interview guide and let them select the topics for discussion, which soon became a general interview practice.

In ethnography, participants' awareness of research objectives can fade with the researcher's sustained presence. As fieldwork progressed, several providers said I felt like 'one of them' or, in one case, that I had become 'part of the woodwork' in the Clinic. Familiarity enriches ethnographic observations, but it also makes consent less certain if participants disclose information or behave in ways they would not have had they been thinking about 'research'. My ethical duty to ensure that research did not compromise or harm either party was compounded by the interdependent relationship between providers and residents. In addition to changing participants' identifiers in my writing, I took the added precaution of reviewing and confirming their consent to my use of any quotes or references to specific observations that could be potentially sensitive. Even if anyone reading the dissertation could not identify the resident, I did not want residents to be surprised and feel exposed if I included something that portrayed them in a vulnerable or potentially compromising light. Anthropologists disagree whether participants in positions of power should be able to influence what is finally written or presented about them (Cassell & Wax, 1980; D'Andrade, 1995; Mosse, 2005; Schepher

Hughes 1995). My decision to review selected representations of providers with them reflected the methodological primacy I gave to respect for personhood and relational accountability (Wilson, 2008; Younging, 2018). In doing so, I sought to avoid any negative impact on their employment, which I had an ethical duty to protect, and to reduce the chance of providers feeling that their trust and goodwill had been betrayed (Cassell, 1980; Smith, 1999; Wilson, 2008). Since I spent less time with providers individually, reviewing potentially sensitive material together also opened space for me to consider that my interpretations could be incorrect or inadequately understood the context (Lassiter, 2005; Wilson, 2008). None of the providers with whom I reviewed potentially sensitive representations expressed any hesitation in having data drawn from their interviews or observations of their practice included in the dissertation even when it portrayed their practice in a less favorable light. This approach also enabled me to gain important contextual information in several instances and correct one detail.

While the vast majority of health encounters were congenial, over two years I observed a few encounters where providers' clearly exceeded an appropriate use of their power. Residents were eager to have these incidents included in the study. Although I changed identifiers, it was possible that if a provider read some quotes or excerpts of observations, they might recognize it as coming from their own interviews or practice. I attempted to resolve my ethical commitments to both parties in one of three ways. When residents talked about these incidents in interviews, I quoted the interview rather than referencing my field notes. If the situation was only documented in my field notes and the provider was still employed at Native Health, which applied to two instances, I reviewed my account with the provider, explained my rationale for including it and asked if there was any additional information they felt needed to be included. While I was prepared to truncate representations if they objected, both supported the inclusion of material drawn from their practice. For sensitive material that involved providers who had retired, taken jobs outside the agency and/or relocated outside of Vancouver, I relied on the initial consent form. I did not consult residents involved in these incidents as all have since passed on.

I also reviewed potentially sensitive quotes and observations with residents to confirm consent to include these in the dissertation. The rationale was the same as for providers, but was also influenced by the resident who thought our informal interactions

were 'off the record'. With the exception of residents who had passed away and one resident still living, I was able to locate all residents who readily confirmed their consent.

### ***Analytic accountability***

*Indigenous epistemology and ontology are based on relationality. Our axiology and methodology are based on maintaining relational accountability. (Wilson, 2008, p. 11)*

My focus on the continuities in colonial dynamics risked overlooking the differences and connections between broader social forces and the micro-level of interactions, and between participants' general experiences of the other party and the particular instances of each encounter and relationship. It was a struggle to ensure my analysis both remained true to the injustices that shaped residents' lives and experiences and did not diminish the constraints on providers, while trying to keep the personhood of *all* parties at the forefront. Data from my observations of medical encounters reflected the 'instances' of interactions, whereas interviews with participants and in my fieldwork outside the Clinic, often reflected their general experiences of the other party. Compounding the challenge of maintaining this analytic balance was the fact that medicine and medical power have been the focus of sustained critical examination for more than 40 years. This literature helped draw attention to the micro-politics of medical encounters but at times clouded my ability to consider clinical data in context and on its own terms. Immersing myself in data about residents' lives and experiences produced emotional responses to the inequities of the DTES and the injustices of residents' lives. Feelings of anger, sadness, and the desire 'do something' to relieve the angst I felt interfered with early writing. The only way I found to navigate and resist the current of critical literatures, dramatic inequities, and associated emotions and to maintain my accountability to both parties was to remain anchored in field data while writing about clinical interactions.

Once I had drafted chapters, I again reviewed all the interview transcripts in entirety to ensure accountability of my analysis and representations. When the first draft of the dissertation was complete, I asked two residents who I approached based on their reliability, literacy and candour to read core chapters or the entire dissertation. The resident who read the entire draft was frustrated by the language and felt that my analysis of the Drop-in Centre had betrayed residents by not telling 'the whole truth'. This view, which she maintained through to the completion of the dissertation, is

discussed in Chapter 9. It reflected a miscalculation on my part in what it meant to be transparent, but in general, with this combination of strategies I felt had achieved a fair balance. Then, as the dissertation neared completion, a colleague who reviewed Chapter 8 commented that some sections seemed unbalanced and overly critical of physicians (S. Smith, personal communication, 26 April, 2018). This colleague's perspective allowed me to realize that I had not given enough attention to the differences in levels: specifically in my responses to witnessing the injustice of residents suffering which were caused by macro-level structures, and how all of us – providers, residents, myself – were positioned within these structures. A contributing factor to a lack of balance was my fear of other residents feeling I had betrayed their concerns and legitimized those with more power. When I had asked one Indigenous resident what he felt was most important for me to reflect in the dissertation he said:

I always wanted somebody to write the real story... the real health story, the Ministry of health, like how they treated us, how we're left in the gutter and ... all they're doing is giving us pills, keeping us alive. I don't want to [be part of a study] where they [providers] get a pat on the back. I don't want any of that and once I see that, I'm out of here (Interview, 29 December, 2009).

The analytic issue was not about moral binaries in what (or who) was right or wrong, but in highlighting the selective in/visibilities and complexities that accompany our social position.

### ***Reflexivity***

Contemporary anthropology recognizes the importance of reflexivity. Specifically, how researchers' social, cultural, and political positioning and personhood interact with the field of study to shape their observations, relationships and textual representations. Researchers need to be aware of these influences and in this study, I continually reflected on how my socio-economic status, nursing background, and upbringing in a colonial society were reflected in my thinking, relationships with and responses to residents and providers. Practicing reflexivity illuminated how the colonial dynamics I observed in health care were also enacted in my own research practices and in my relationships with participants. For example, I sought to address inequities by prioritizing residents' perspectives, yet I inadvertently reproduced inequities by implicitly viewing residents' personal lives as matters of research (public) interest and by seeing providers' personal lives as private matters. I critiqued the normative and moral dynamics of health

care, while continually struggled with my own – ongoing – tendency to frame analysis of participants’ understandings, responses and choices in binaries of ‘either / or’ and inferences of ‘good / bad’, or to resolve the messiness in the data with definitive statements, rather than understand and respect the diversity, contradictions, exceptions and as part of social life as it actually is. Occasionally providers shared details of their personal lives, but I never asked about their HIV status, chronic health concerns, drug and alcohol use, social challenges, sexuality, finances, or housing, topics that were all discussed with residents. It is not that I wanted to ask and restrained myself; to ask providers’ personal questions seemed such a violation that it never occurred to me. I came to understand that it has become so natural for researchers to ask about residents’ private affairs that it is difficult for us to see our intrusions into their lives.

As previously mentioned, the starting place for my inquiry was the medical category of HIV rather than the realities of residents’ everyday lives or *their* priorities in health care interactions. Through most of fieldwork, I didn’t think to explore what residents *enjoyed* about drugs, how drugs *enhanced* their lives and relationships, or what sustained them during times of intensified hardship. Overdoses resulted in many deaths, but knowing the difficulties of some residents’ lives, I later wondered why overdosing wasn’t *more* common: what ‘held’ residents in life at times of desperation? I also didn’t realize until well into fieldwork how my emphasis on HIV in many interviews negatively impacted some residents. Once, as a diversion from our usual interviews, a resident agreed to a walking tour, showing me where she lived and worked over the preceding 25 years. At the end of the tour, she announced, ‘That was a good story! I liked that talk. It brought good memories back’ (Field Notes, 7 January 2010). I then learned that most of our previous interviews had left her feeling ‘heavy’ and needing to debrief with her daughter. The walking tour was ‘a good story’ because it centred on the priorities of her life: community, connection, happy times. Happy memories were not independent of alcoholism, addiction, exposure to violence and abuse, homelessness or illness, but these struggles were nested within a larger narrative defined by belonging and reciprocal networks of care. The sense of community that characterized the happy times sustained her through difficulties. In our regular interviews, when I generated and asked the questions, I had unthinkingly minimized the relational context fundamental to her resilience and identity. Through this, other interactions, and my reflexivity, I came to see how my emphasis on pathology and difficulties could cut residents’ sensibilities like

a knife, excising the very things that carried them day to day, buffering painful histories, hardships, loss and violence. If one accepts the premise of decolonizing research as strengthening connections and promoting good feelings, there was little doubt about the ways that health research (including mine) reproduced colonial oppression.

### 3.4. Conclusion

The study started in my head with a topic, rationale, proposal, and the belief that an anthropological perspective could generate insights to improve the delivery of HIV services. As the study progressed it became personal in ways I could never have imagined. Despite the pervasiveness of the forces that undermined residents' dignity, when I read over residents' interview transcripts and my field notes I often found myself smiling, laughing aloud and moved anew by residents' eloquence, pain and concern for others. The warmth and generosity of Native Health providers were no less important. For both groups of participants the affective dimensions of our encounters held me accountable, anchoring and sustaining me when overwhelmed by the tsunami of data or struggling through the isolation of analysis and writing.

The priority of my relationships with residents made it difficult for me to step away from the DTES. What does it mean to 'exit the field' when we've formed relationships with people who've felt judged and exploited by authorities, yet have risked opening their lives in trust and friendship? When fieldwork was wrapping up I asked one Indigenous resident what she thought about researchers in the DTES:

Res: [Researchers are] doing the same thing over and over and over again. But you're not doing what you're finding out about. You're not following up on it, you're just researching. But what about the people you just researched?! Are you just going to leave them stranded after they give you their whole heart, like now? And then you're going to forget about me? That's not fair!

LC: You think I'll forget about you?

Res: No, I know you won't, but what if another person . . . gets attached to you and then you're not around? They've given you their whole life story and then you're never going to see them again? What the fuck! That person that you're interviewing, he sheds his whole skin off and you just leave him stranded? What the hell! . . . After he bled for you! And

you're not going back to him to say, 'hey, this is what's happening here'. . . . I wouldn't want to shed this much information with somebody I didn't know and then [not have them] come back and tell me what it's all about. I'd feel used (Interview, 20 March 2011).

The idea that residents had bled their stories for this study haunted me, and I resolved to do my utmost to avoid residents feeling used for data. As mentioned in Chapter 1, I maintained contact with residents through phone calls, emails, Christmas cards, personal notes and made a point of visiting selected residents and the Drop-in Centre on return trips to Vancouver. However, with some exceptions, staying in touch has been a one-sided affair.

Who decides what happens when the research is done? What ongoing accountabilities (if any) do researchers have to those who participate in our projects? As my research progressed, I saw some of my relationships as an ongoing commitment to the resident as a person but most of the residents I felt the closest to have since passed on with two passing in the final year of the dissertation. I cannot anticipate whether or how relationships with remaining residents and with Native Health will endure over time because I won't really 'leave the field' until the dissertation is done. For now, I think of it as an exit that opens into indeterminacy.

## Chapter 4. Producing ‘difference’ over time

This chapter provides important context for analyzing the colonial dynamics of health services, and it especially illuminates the role of the health research industry in the Downtown Eastside (DTES). As I will show, given the overlap of health research and care, the enactment of colonial dynamics often becomes mutually reinforcing. Even when residents differentiate between health research and care, the prominence of the research industry in residents’ everyday lives can accentuate their experiences of exploitation and their suspicions of providers. This context makes clear that residents’ critiques of discrimination and exploitation are produced in a wider field of contact with institutions and professionals. While health research is a diverse field of endeavour, I will argue that the *net* impact of the health research industry in the DTES is the perpetuation of residents’ suffering by re-enacting colonial dynamics in ways that reinforce inequities and residents’ social marginalization.

While I concentrate on the period from Europeans’ arrival to the present, I recognize that Coast Salish peoples have occupied the area of present-day Vancouver and the DTES for thousands of years before colonization (Barman, 2007; Blomley, 2004; Perry, 2001). In addition to well-established seasonal villages at the head of False Creek, along the shores of present-day Stanley Park, and the south and north shores of Burrard Inlet (Barman, 2005; Roine, 1996; Zaharoff, 1978), a seasonal camp called Q’emq’emel’ay was located in what is now known as the DTES (Blomley, 2004). As noted in Chapter 2, the impact epidemics among Indigenous Peoples contributed to racial beliefs about their physical weakness (Daschuk, 2013; Kelm, 1998, 2010), but in this chapter, I focus on how colonial beliefs shaped representations of the area and its residents and the social and political processes that made their ‘difference’ visible.

By briefly reviewing the history of the DTES and the emergence of the local health research in the 1990s, I build my argument that continuities in the representations of residents over time reflect ongoing colonial dynamics (Blomley, 2004; Kelm, 2010; Liu & Blomley, 2013). When I began reading about the history of the DTES, I was surprised to find that representations of earlier residents there, such as Chinese immigrants and sex workers, deployed the same colonial tropes that are used to justify interventions and increase the governance of residents today. Such representations emphasize people’s

perceived vulnerability and exoticize illicit drug use, drunkenness, criminal activities and sexual behaviors (Culhane, 2003, 2009, 2011; Liu & Blomley, 2013). Portrayed as 'problem people' who pose a danger to respectable (white) settler society, the concentration of these groups in the DTES has been used as a self-evident rationale for containing their harms (Anderson, 1991; Sommers, 2001) and governing their lives (Woolford, 2001; Roe, 2009). Scholars have argued that spatializing of social problems, by imagining them as contained in a particular place, symbolically cleanses other areas by maintaining an illusion of separateness between the so-called 'respectable' and 'disreputable' members of society (Anderson, 1995; Porter, 1999; Smith, 2003; Strange & Loo, 1997; Woolford, 2001). It is an illusion because the problems that have become identified with the DTES are not confined to its few city blocks but are dispersed throughout society.

While the figure of the Addict as a signifier of immorality and disorder has a broader social history, I contend its valence in residents' daily lives and in health care interactions represents a particular and locally significant conjunction. In this chapter, I argue that the compounding impacts of gentrification, neoliberal reforms and the economies of concern that emerged around the HIV epidemic in the early 1990s reiterated colonial representations of the DTES and constructed residents as Addicts. When residents seek health services, and especially treatment for pain, the racial tropes encoded in the figure of the Addict influence providers' responses. The local health research industry, with its interest in correlations among Aboriginality, drug use and HIV, has played an important role in this. At the same time, health research has become a way to fund services in a political context of reduced funding, and residents often decide to participate in health research for the benefits such studies might offer.

An introduction to the DTES would be incomplete without acknowledging the rapid pace of gentrification in recent years. Nicholas Blomley (2004) argues that while colonial dispossession is complete, the processes of displacement are ongoing. In the DTES, displacement via gentrification leverages the logics of colonial dispossession in arguments that a greater 'social mix' of residents is necessary for the area's revitalization and for 'better' use of inner-city space. The arguments for gentrification are blind to the claims of Indigenous Peoples and others who do not abide by prevailing norms of private or public property. Anti-gentrification activists have accentuated the claims of white working-class residents, further erasing the claims of Indigenous Peoples

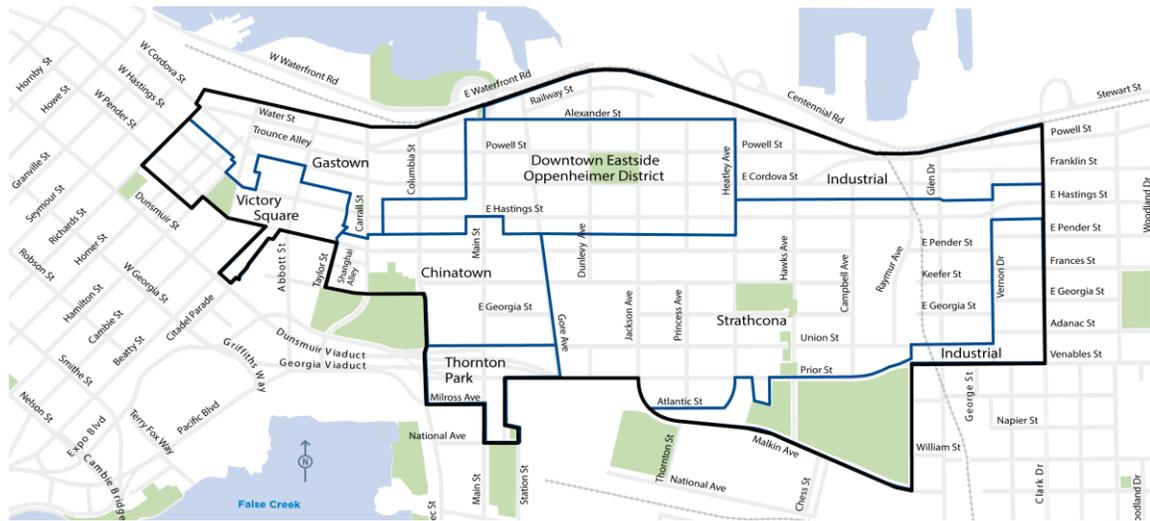
and residents. Together, gentrification is commodifying the DTES by harnessing the area's reputation in the sale of condos and the promotion of businesses that cater to newer and affluent individuals. Some of the effects of this include greater policing, the conversion of many buildings that once offered low-cost housing into privately owned condos, and a corresponding reduction in low-cost housing and higher rents (Carnegie Community Action Project [CCAP], 2016, 2017; Pivot Legal Society, 2006).

I begin the chapter by briefly tracing continuities in public representations of the area and its residents to illustrate how they reinforce long-held public perceptions while ignoring information that might contradict or complicate them. I then discuss how multiple forces converged around the epidemics of HIV and drug use in the late 1980s and early 1990s to produce the figure of the Addict. Following this overview, I take a closer look at the role of health research in constructing and racializing the Addict during the 1990s HIV epidemic. Finally, I consider the political economy of 'difference' by highlighting asymmetries in the economic and professional capital vested in health research and its benefits for residents. These layers of context lay a foundation for understanding residents' critiques, and for my broader argument about how health care continues to enact the colonial dispossession at the level of residents' bodies and contributes to the institutional enactment of moral violence.

#### **4.1. The historical roots of dereliction, disorder and disease**

The DTES marks the first site of colonial settlement and industry on the shores of Burrard Inlet. Several historic neighbourhoods comprise the area which, as shown in Figure 1, include Victory Square and Gastown along its western border, and an industrial area to the east where the first sawmill on Burrard Inlet, Hastings Mill, once stood. Running east to west through the DTES is Hastings Street, a busy thoroughfare for bus and car traffic connecting Downtown Vancouver with suburbs to the East. Intersecting Hastings, at the approximate midpoint of the DTES, is Main Street which extends from the northern border on the shores of Burrard Inlet, to South Vancouver. The junction of Hastings and Main represents the socio-spatial heart of the DTES. The impressive grey stone edifice of the Carnegie Community Centre, on the southwest corner of the intersection, draws many poor and retired residents including Elderly Chinese residents from adjacent Chinatown. Throughout the day impoverished residents can be observed

congregating around the entrance to ‘the Carnegie’ and on other corners of Hastings and Main Streets, socializing, passing the time, or performing various roles in the informal economies of street life. Police maintain a regular presence in the areas’ streets and parks as part of ongoing surveillance. Research for this study concentrated along Hastings Street in the neighbourhood of Oppenheimer.



**Figure 1: Map of the Downtown Eastside.**  
 Source: Reprinted from *Downtown Eastside Plan*, by City of Vancouver, 2015, retrieved from <https://vancouver.ca/files/cov/downtown-eastside-plan.pdf>, p. 5

Longstanding claims about the transience of DTES residents have justified a variety of interventions into the DTES (Campbell, 2001; Murray, 2011). However, in 1971 a City of Vancouver survey found only 20% of residents were transient and that over half had lived or worked in the area more than six years (Sommers, 2001).

Many researchers have examined how the DTES and its residents have long been associated with immorality, dereliction and disorder (Anderson, 1991; Hasson and Ley, 1994; MacDonald, 1991; Roy, 2003; Sommers, 2001). The influence of racial beliefs is evident in the ongoing attention of government and police to crime, sex work, drinking and drug use in the area (Anderson, 1991; Hasson and Ley, 1994; MacDonald, 1991; Roy, 2003; Sommers, 2001). We can see how the use of drugs, as one example, has had different valences at different times. Across North America in the 19th century, opium had been widely used in patented medicines, and the smoking of opium was largely limited to Chinese (Courtwright, 2001). Some argue that no particular moral significance had been attached to it until white settlers started smoking it (Carstairs,

2010; Courtwright, 2001). The early 20th century saw the criminalization of drugs prompted by growing white antipathy toward Chinese immigrants – opium smoking was seen as visible evidence of their immorality. Scholars of Chinese history in Vancouver and BC link the problematization of opium smoking to high unemployment among white labourers and to settlers' fears of miscegenation (Anderson, 1991; Perry, 2001). Once criminalized, most arrests for opium use were of lower-class whites, most of whom had prior convictions (Carstairs, 2010; Mosher & Hagan, 1994). This fact both exposes the racism in the public's perceptions of Chinese people and, more importantly, highlights the intersection of race and class in the area's long association with illicit drugs, which continues today.

The reputation of the area as a space of dereliction has persisted over time. In the late 1960s middle-class activists started to assert themselves as area spokespeople, and, through the 1970s and 1980s, to promote the area as the home of the respectable working class; a representation that allowed little room to encompass more marginalized residents (Sommers, 2001). In the late 1980s and early 1990s, with an increase in the use of injectable heroin and cocaine and despite having the first needle-exchange program in Canada, residents began being diagnosed with HIV in large numbers (Roe, 2003; Strathdee et al, 1997). External experts, researchers and providers were drawn to the area and assumed the role of representing residents' concerns. As experts increasingly spoke for residents, residents were reduced to the status of clients, defined by their suffering and need (Roe, 2003, 2009; Sommers, 2001).

Changing patterns of drug use came about as high-grade heroin, followed by cocaine and crack-cocaine, became more accessible and affordable (Campbell et al, 2009; Lupick, 2017; O'Shaughnessy et al, 2012). Controlled access to clean needles in the late 1980s and early 1990s facilitated the spread of HIV and hepatitis C as intravenous use of cocaine required more frequent injections than opiates. Several residents and providers in my study said that the shift to cocaine and crack-cocaine increased street-level violence and destabilized the sense of community. Large numbers of drug users gathered in alleys near the 100 block of East Hastings Street, and as businesses closed or moved out of the area, residents told me, that the presence of contracted security guards and police increased. They also told me that public spaces, such as parking lots, were gradually enclosed making it more difficult for homeless residents to find places to sleep.

The image of the DTES as a tainted space inhabited by problem people has been reinforced by a number of factors related to neoliberal economic reforms (Woolford, 2001). Neoliberalism, which is predicated on liberal beliefs of the self-regulating 'free-market', promotes the private sector by deregulation, the reduction of government funding, and the privatization of government services. From the mid-1980s onward, the impact of neoliberal reforms started to become visible through interlinked processes of gentrification, the erosion of social programs, health reforms, and the deinstitutionalization of Riverview Hospital, an institution in a suburb of Vancouver that had housed people with serious mental illnesses. A Vancouver-wide real-estate boom in the 1980s made undervalued real estate of the DTES attractive to developers (Blomley, 2004).<sup>26</sup> Vancouver's bid to host Expo 86 on lands near the DTES added impetus for gentrification as several single room occupancy (SRO) hotels evicted hundreds of residents in an effort to gain economic benefits from expo-related tourism (Linden et al., 2012; Sommers, 2001). The visible concentration of residents who used illicit drugs were viewed by developers as challenges to urban 'revitalization' (Blomley, 2004).

At the same time, changes in social programs reduced the number of people eligible to receive welfare, dropping 29% between 1995 and 2001 in British Columbia (Klein & Long, 2003). Welfare subsidies for housing remained fixed at \$375 and fell further behind as rents increased and the availability of low-income housing decreased.<sup>27</sup> In the mid-1980s, as Riverview Hospital began releasing patients into the community, many were attracted to the DTES for its low-cost housing. According to several providers I interviewed, given the inadequate community supports and the presence of drug dealers, many mentally ill residents soon became addicted and died as a result of HIV infections or drug overdoses. Health care reforms in the 1990s brought a growing array of services under one umbrella. The Vancouver Richmond Health Board absorbed the City of Vancouver Health Department in 1996, which was then subsumed in 2001 by the Vancouver Coastal Health Authority, as part of a province wide move that reorganized all health services in BC into six regional health authorities organized on a corporate model that emphasized business plans, cost-effectiveness and measurable

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<sup>26</sup> DTES real estate in 1997 was valued around \$70 per square foot compared to rates over 10 times higher in the central downtown area (Blomley, 2004).

<sup>27</sup> In 2009, when I began fieldwork, the proportion of rooms in hotels where all rooms rented for \$375 or less was 29% and had declined to 7% by 2011 (CCAP 2016). CCAP surveyors found four available rooms renting for \$375 or less in 2009, two in 2011, and no rooms available at \$375 or less in 2015 and 2016 (CCAP, 2017).

outcomes. With a growing demand for evidence that demonstrated the efficacy of services, opportunities for health research expanded while core funding for community services declined and the competition for funding increased (Roe, 2003, 2009; Sommers, 2001). As agency services were brought into alignment with funding streams, advocacy work was replaced by an emphasis on services shaped by providers' understandings of residents' needs, agency resources, and the interventions providers were equipped to deliver.

The concentrated 'at-risk' population in the DTES and concerns about the spread of HIV into surrounding areas of the city presented a natural site and self-evident need for the industries of health research and care. The general decline in government funding for social programs and health care was matched with increased funding for health research and new opportunities for health services (Elliott, 2010; Roe, 2009).

## **4.2. HIV, Aboriginality, drug use and health research**

In Vancouver, the first case of HIV was diagnosed in 1983 (BC Centre for Disease Control [BCCDC], (2007) with the early epidemic primarily impacting gay men living outside the DTES. Thus, as the epidemic started to affect more injection drug-users and people living in the DTES, there were already epidemiologists, scientists, and officials examining its impact in BC. When the DTES needle-exchange opened in 1988, health officials estimated a sero-prevalence rate of 1-2% among all users (Patrick et al., 1997). One of the first studies of HIV/AIDS in the DTES, conducted between March 1988 and November 1990, tested 448 'street-involved' Aboriginal residents and found the prevalence of HIV was approximately 1.5 times higher among Aboriginal people than non-Aboriginal people and that 3.9 % of all infections among Aboriginal people were linked to injection drug use (Rekart et al., 1991). The increasing use of injectable cocaine and widespread sharing of needles, combined with the heightened communicability of early HIV infection facilitated the spread of HIV (BCCDC, n.d.). By 1996 the prevalence of HIV in the DTES had risen to 23% (Strathdee et al., 1997).<sup>28</sup>

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<sup>28</sup> References to the prevalence rates of HIV in the DTES epidemic ranged from 3-4% to 40% during the 1990s (O'Shaughnessy et al, 2012). The most frequently cited prevalence rate from the peak of the epidemic is 23% (Strathdee et al., 1997).

In response to the dramatic rise in infection rates and pressure from stakeholders within the DTES, the Vancouver Richmond Health Board (VRHB) took the unprecedented step of declaring a public health emergency in October 1997. With national and international attention focussed on the area, funding for HIV services and research poured into the area from various levels of government. I interviewed several providers who had been working in the area at the time, and they recalled feeling relief that residents would finally get the help they needed. But for some, hope was short-lived. One provider explained, 'after a while it wears off. It's the same old thing. [You begin wondering] actually, what happened to the money, where did it go?' (Interview, 10 June 2010). The comment reflected a tension I observed numerous times between the experiences and priorities of many providers involved with direct care within the DTES and those of administrators and health researchers. There was no doubt about the need for evidence to gauge the magnitude and progression of the epidemic. Several providers told me how they laboured under strain, working extra hours and weekends to assist residents, and repeatedly expressing their concern to administrators as the local impact of the epidemic increased. Despite the attention, funding and research attracted by HIV, these providers found that much of the funding directed to the area for health research and for redesigning health services, as part of health care reform, was irrelevant and self-serving. Some providers told me they felt great moral dissonance in seeing so much money directed to the area, with so little visible benefit for residents. With neoliberal reforms, the health authority assumed a greater presence and many nurses and allied providers who had worked in the area prior to and through the HIV epidemic found their experience discounted, their professional autonomy and ability to adjust their practice to residents' needs curtailed as administrators who had never worked in the DTES began implementing reforms. Interestingly, the experiences of these providers were mirrored in the experience of residents, as many in both groups reported an increasing regulation of their work / lives from the late 1990s to present.

The deployment of colonial tropes that had been used to describe earlier groups of DTES 'problem people' bled into representations of the area and, in turn, into the local construction of the Addict. In his systematic analysis of newspaper articles about DTES between 1997 and 1999, Woolford (2001) found the area most often described in terms of residents' moral culpability, disorder, filth, violence, and the physical and social threats residents posed to the rest of Vancouver (see also Liu & Blomley, 2013). The titles of

newspaper articles from this time show how closely 'Aboriginality', 'drug use' and 'HIV' were woven into the emerging portrait of the Addict informed by health research: 'Natives Face AIDS Threat, Meeting Told' (Fournier, 13 April 1989); 'AIDS Risk for Natives: Indian Women Prime Candidates' (Fournier, 13, January, 1991); 'AIDS Threatens BC Natives: Disease Called a Ticking Time-Bomb' (Hendrickson, 12 March 1991); 'Infection Rates in Street-People Much Higher among Aboriginals' (Mickleburgh, 28 June 1991); 'Natives Suffering More Cases of AIDS' (Aubry, 11 May 1993); 'Wasting Away at the Bottom of the AIDS Totem Pole' (n.a, 19 April 1994); 'HIV Among Drug Users Raises Alarm' (Fong, 14 October 1994), 'and Native Drug Users Hardest Hit by HIV' (Picard, 7 January, 2003), 'Pregnant Natives HIV Rate Alarms Researchers' (Munro, 26 July, 2004). Health research, with its emphasis on pathology, contributed to this emerging portrait with findings that linked HIV to beliefs about residents' sexual promiscuity, irresponsibility, low rates of adherence, drug use and criminality (see Kerr et al., 2004; Tyndall et al, 2002; Wood et al, 2006).

In these ways, Aboriginality was woven into early health research, media representations of the HIV epidemic and constructions of the Addict. I now take a step back to discuss how colonial beliefs shaped health researchers' assumptions and understandings of 'Aboriginality', and specifically how beliefs about Indigenous Peoples' cultures and propensity for disease were accentuated by giving less attention to the political, economic and structural factors entailed in creating inequities between Indigenous and settler residents' health status. From the beginning of the epidemic there have been health officials and researchers who connected the epidemic and disproportionate impact of HIV for Indigenous residents to histories of colonization and heightened exposure to poverty, systemic discrimination, and abuse. My argument here, follows the main emphasis of health research and how communication from officials regarding the epidemic converged with historically conditioned racial tropes.

In Chapter 2, I noted that, across Canada, researchers began monitoring the numbers of Aboriginal people infected with HIV well before significant numbers of Indigenous Peoples were infected (Kelm, 2010). Where research was a *response* to growing rates of HIV/AIDS among other groups, high rates of HIV were *expected* among Indigenous Peoples, indicating that the association between Aboriginality and pathology persisted despite a lack of evidence. Rekart et al.'s (1991) study on the prevalence of HIV among Aboriginal residents promoted the notion of ethno-racial 'difference' in

elevated rates of HIV by downplaying the fact that most of the Aboriginal men in his study had acquired HIV through homosexual practices. When interviewed about the results, Rekart, then director of BC's Sexually Transmitted Disease Program, was quoted as saying: 'It scares the hell out of me . . . some of us have been saying for a long time that (an AIDS epidemic) is coming to the native population. Well, now it's here' (Mickelburgh, 28 June 1991). There was, he continued, 'nothing physical or genetic about natives that make them more at risk.' Aboriginal residents had higher rates because they were 'more likely' to engage in high-risk activities 'without taking sufficient precautions' (Mickelburgh, 28 June 1991). The epidemic among Aboriginal peoples was *expected* because of pre-existing assumptions about their irresponsible behavior and vulnerability to disease, which was both cause for alarm and professional intervention. A similar message was evident in a 1997 Health Canada Epi Update examining HIV/AIDS epidemiology among Aboriginal people (Health Canada, November 1997). Under the heading, 'Pattern of AIDS Is Different among Aboriginal People', there are two subheadings – 'Increasing Trend over Time' and 'Injection Drug Use (IDU), a Major Risk Factor' – but in the findings under this second heading the main risk factor identified is men having sex with men. There is no explanation of why injection drug use and Aboriginality were selected as significant and the focus of the article rather than MSM.

The conflation of Aboriginality and pathology in health research about HIV was exemplified in a study entitled 'Aboriginal Status Is a Prognostic Factor for Mortality among Antiretroviral Naïve HIV Positive Individuals First Initiating Highly Active Antiretroviral Therapy (HAART)' (Lima et al., 2006). The authors examined whether Aboriginal and non-Aboriginal people had different biological responses to HIV and found they did not. In controlling for socio-demographic variables, researchers noted that fewer Aboriginal subjects had completed high school, were more likely to have had an annual income less than \$10,000, and were more likely to be treated by less experienced physicians and be undiagnosed at the time of the study. However, none of these factors were significantly (statistically) associated with being Aboriginal. That Aboriginal people with HIV infection were more than three times more likely to die than non-Aboriginal participants in the study was attributed to infectious and parasitic diseases (47.8%), self-inflicted injuries (19.4%) with the balance of 32.8% unexplained. Researchers concluded that lower survival rates were due to 'other' aspects of being Aboriginal (Lima et al., 2006, p. 8). In reviewing all of the articles cited by Lima et al., I

found that most studies' hypotheses of racial/ethnic differences were *not* supported, which suggests that researchers' beliefs in racial/ethnic differences, once again, persists despite evidence to the contrary. Furthermore, the impact of physicians' experiences and practices in the DTES, which are periodically mentioned in other studies, has not resulted in physicians becoming a prominent focus in local health research that seeks ways to manage the epidemic.

'Other aspects', identified by Lima et al (2006) does not preclude consideration of political, economic and social contexts, nor the experiences of Indigenous Peoples, but it also does not question the basic premise that there is something about *being* Aboriginal that results in early death. Framing premature death as a problem of Aboriginality trivializes the historic, social, economic and political contexts that produce ill health. It also neglects diversity in class and cultures among Aboriginal peoples and the way that colonial dynamics and inequities transect society: instead the problem resides with/in Aboriginality. The heightened emphasis on Aboriginality as an explanatory factor for ill health is characteristic of much health research considering Indigenous Peoples' health in Canada (Tait, 2000, 2013; Waldram, 2004) and internationally (Lea, 2005; Packard & Epstein, 1991). The majority of people infected with HIV in Vancouver then, as now, are caucasian (or white) men who have sex with men (BCCDC, 2015). Yet, non-Aboriginal people, Euro-Canadians or whites were not identified as a high-risk group or targeted for HIV interventions in any of the literature I reviewed. Whiteness is eclipsed by behaviors such as homosexual practices or sex work; when whites engage in risky behavior it tends to be attributed to the behaviors of some and not construed as a general (racial) attribute of all whites. Indigenous Peoples infected with HIV are no more reflective of all Indigenous people than are white men who have sex with men reflective of all whites.

Even when the socio-historical context of Aboriginal peoples' ill health was acknowledged in epidemiological studies, as in references to colonization and residential schools, the nod to socio-historical context was over-shadowed by the focus on individual pathology. Culture (as a code for Aboriginality) often surfaces in researchers' accompanying recommendations for 'culturally appropriate' (Moira & Harrison, 2010)<sup>29</sup>,

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<sup>29</sup> Nurse-researchers, Williamson and Harrison's (2010) literature review of 'culturally appropriate' care found the construct was understood in two distinct ways. The first focused on the cognitive aspects of culture (values, beliefs and traditions) and emphasized the need for providers to

'culturally competent' (Kumagai & Lypson, 2009; Schilder et al., 2001; Teal & Street, 2009) or 'culturally safe' care (Ariel et al, 2012; Baker & Giles, 2012).<sup>30</sup> The last term has gained increasing prominence in health care by a stated focus on addressing the social and structural contexts of disadvantage. However, I contend that the notion of cultural safety attempts to address the impacts of colonialism while *diverting* attention from the structures which sustain disadvantage.<sup>31</sup>

On reviewing literature that endorsed cultural safety, I found that when it is translated into practice, the term reiterates colonial tropes in emphasizing the vulnerability of Indigenous subjects and the responsibility, agency and presumptive ability of providers to make care 'safe'. Critics argue that there is little evidence that 'cultural safety' makes any difference in care (Downing et al., 2011; Kirmayer, 2008a, 2008b, 2014; Polascheck, 1998). Indigenous nurses, Dion Stout and Downey (2006), caution that cultural safety can take too much for granted by failing to consider that Indigenous Peoples' 'are knowers, doers, and givers of health and healing and so must be recognized as their own witnesses' in health care encounters'. Grassroots perspectives, they write, must be concurrent with changes in health care structures and policies which support Indigenous Peoples' perspectives and traditions, and respect their right to self-determine (Dion Stout & Downey, 2006, p. 327). The views of these scholars are supported by Josewski (2012) who found that neoliberal reforms in health care undermine culturally safe policy goals and produce situations that place Indigenous patients *and* providers at heightened risk for harm; the latter point also supported by Vukic et al (2012). Kirmayer (2013) suggests that by accentuating beliefs about Indigenous Peoples' vulnerability, 'cultural safety may contribute to the essentializing and stereotyping of ethnocultural groups' (p. 159).<sup>32</sup> Proponents, Browne et al (2009), found that while the construct was useful for teaching health care professionals, the

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understand their own cultural beliefs and values and/or those of subjects. The second located culture within the broader historical, social, and structural context of health services.

<sup>30</sup> For example, see Hogg et al, 2005; Wood et al., 2008.

<sup>31</sup> As proposed by Maori nurse Irihapeti Ramsden (Papp & Ramsden, 1996), 'cultural safety' focuses on the 'culture' of institutions and increasing providers' awareness of how structured asymmetries of power disadvantage Indigenous people's engagement with health care. This view characterizes the writing of proponents who discuss how historic, social and structural asymmetries in power contribute to negative experiences health care (Health Council of Canada, 2012; Brascoupe & Waters, 2009; McCall & Lauridsen-Hoegh, 2014; Pauly et al., 2013; Smye & Browne, 2002).

<sup>32</sup> For example: McCall & Lauridsen-Hoegh, 2014; Teal & Street, 2009.

concerns of practicing nurses concentrated on increasing workloads. What work does 'culture' perform in arguments for culturally [fill-in-the-blank] care, when there is consensus that the fundamental issue is ongoing colonialism? (Health Council of Canada, 2012; Pauly et al., 2013; Smye & Browne, 2002). For Kirmayer (2013) culture mediates the uncertainty of practice by offering a sense of control in areas where providers' knowledge and influence is limited. Given the conceptual blurring of signifiers for alterity, such as culture, ethnicity and race (Barbee, 1993), I contend that invoking 'culturally [blank] care' offers an illusion of tackling historically conditioned inequities, while obfuscating health researchers' and providers' complicity in structures that 'make' difference necessary and, as a result, contribute to maintaining rather than alleviating inequities. It is for Indigenous Peoples to say whether, where and how culture matters in health services. Meanwhile, the default to culture rather than colonialism too easily suggests that the enduring problem of health inequities resides in some inherent aspect of *being* Aboriginal rather than the way colonial dynamics are encoded in social structures, policies, professional knowledge, therapeutic aims, and practices. Moreover, the link between cultural safety and Aboriginality in much of this literature elides how the colonial dynamics of care also disadvantage poor settlers and Indigenous providers, how patients' experiences of care are increasingly silenced with neoliberal reforms and risk management (Aronowitz, 2015; Josewski, 2012; Sweet, 2007, 2013) and, how these shifts can constrain providers in changing their practices in the ways needed to make institutions 'safe' (Spitzer, 2004; Browne et al, 2009).

Health researchers' interest in Aboriginality, and by extension Aboriginal cultures, is nothing new (Kelm, 1998, 2005; Waldram, 2004), but in this context, with the higher rates of HIV and lower use of treatment by Indigenous residents, the Addict becomes a racialized signifier of disorder and disease. This is reflected in many article titles and findings from health research in the DTES such as: 'Aboriginal IDUs Are Becoming HIV Positive at Twice the Rate of Non-Aboriginal IDUs' (Craib et al, 2003) and 'The Rate of ART Use Was 29.2% among Aboriginal Participants and Was 53.7% among Non-Aboriginal Participants' (Wood et al, 2006). The deployment of race in the construction of the Addict was matched by other studies that described the high rates of HIV in the DTES as 'the highest outside of sub-Saharan Africa' (Campbell et al., 2009), 'the highest' (Wood & Kerr, 2006) and 'the most rampant in the developed world' (Munro, 2 October, 1997). What makes the Addict unique in the DTES is the particular conjunction

of an enduring local history of a 'tainted' area and its residents with neoliberalism, gentrification, and the industries of health research and care.

### **4.3. Producing difference through health research**

On reviewing many full-length articles and 253 abstracts of studies based on health research in the DTES, I identified four strategies involved in the production of difference. First, was the elision of diverse meanings of drug use. By failing to consider the breadth of meanings associated with drug use, health discourses reinforced the pathologization and medicalization of drug use. As I discuss in Chapter 5, many residents I spoke to acknowledged harmful aspects of drug use but more often described it as a lifestyle, a conduit to community, a coping strategy, and a source of well-being, relaxation and entertainment. Seeing illicit drug use solely as a signifier of pathology reinforces colonial hierarchies of power by privileging medical definitions over the lived meanings of residents. Individual researchers may have more complex understandings of residents' social realities and drug use, but such understandings are submerged by the epistemological, methodological and representational conventions of research and research publications, which allow little room for residents to influence or critique research processes and representations.

This elision of diverse meanings of drug use is facilitated by the socio-spatial distance between researchers and residents. Epidemiologist Robert Remis (2002), in his commentary on health research in the DTES, argued for the need to fully involve residents who use drugs to identify strategies to address addiction. Indeed the diversity of meanings among residents and their own perspectives of what might help to improve their health are often overlooked (Benoit et al, 2003; Culhane, 2011). With some exceptions (i.e., Salmon & Livingstone, 2009; Shannon et al, 2005), conventional hierarchies of power and distance between researchers and residents seem to be accepted without question. Providers who had worked with various research projects in the DTES explained to me that data was often collected by nurses without advanced research training or by research assistants at fixed locations, such as a supervised injection site or the office for a large cohort study known as 'VIDUS' (Vancouver Injection Drug User Study). Computer technologies allow data analysis to occur elsewhere. It is thus possible for research to be conducted without researchers ever having to interact

with residents. Although residents' personhood and agency is acknowledged to different extents in qualitative and ethnographic health research, analytic links between macro-level processes, residents' histories, social contexts, interpretations and behaviors, with a few exceptions (i.e., Shannon et al, 2008), remain limited and secondary to biomedical priorities.

I found local health research (including research by social scientists) was seen by many providers to have little relevance to their practice and efforts to improve residents' health. As one physician told me, 'Do I read all these studies? No. Sometimes it's a bit much . . . 'gosh golly, street kids use more drugs? Like you paid someone to come up with that? . . . We knew that 10 years ago!' (Interview, 30 April 2010). The few providers who expressed support for local health research *in principle*, were unable to identify any concrete way that it contributed to their practice. This may, in part, reflect the excessive attention given to some topics, such as HIV and drug use, and the dearth of research directed to other prevalent concerns, such as mental and oral health (Linden et al, 2012), which are often identified as concerns by providers and residents' alike. Although numerous studies offer services, the perceived irrelevance of most health research appears at odds with ethical principles of research involving Indigenous Peoples (Canadian Institute of Health Research [CIHR], n.d.), which is to conduct research that is locally directed and relevant. The definition of 'community' in the DTES is contentious (Roe, 2003; Sommers, 2001) and local accountability, to the extent it exists, usually resides in researchers' relationships with specific agencies and the providers who work within them. There are exceptions with health studies that prioritize collaboration with residents (i.e., Benoit & Carroll, 2001) and/or are led by provider-researchers within agencies (i.e., Tu et al, 2013) but most health research, analysis and research representations tend to be controlled by researchers external to the DTES (O'Neil et al., 1998; Remis, 2002).

After pouring over publications from the British Columbia Centre for Excellence in HIV/AIDS (BC-CfE) for several years I found that the elision of diversity also occurred through the *proliferation* of difference. Research has identified which groups have a higher incidence of HIV and who has uneven uptake of ARVs despite their wide availability. However, I found it difficult to obtain any critical purchase amid the mountain of correlations made involving Aboriginal residents, non-Aboriginal residents youth, adults, men, women, crack users, crystal meth users, cocaine users, heroin users,

homeless residents, housed residents, drug users, sex workers, and so on. The myriad of correlations only held form when poured into a primary category of 'drug user' that was spatially positioned in the DTES.

The second factor in the production of difference was the *elision of similarity* between patterns observed in the DTES and in society generally. Epidemiological studies in the DTES have repeatedly shown that women, youth, and Aboriginal residents are more disadvantaged in virtually every indicator, such as risk of HIV infection and exposure to violence (i.e., Braitstein et al., 2006; Chettiar et al., 2010; Duncan et al., 2010; Shannon & Csete, 2010; Spittal et al., 2002; Weber et al., 2003; Wood et al., 2008). The groups of residents associated with heightened disadvantages, show that 'the rest', who by inference are male, white and often middle-aged, face (relatively) less disadvantage. The escarpment of disadvantage among marginalized residents is not unique to the DTES but reflects raced, classed, gendered and age-related gradients of inequity which transect society.

The methodologies of much health research allow little space for researchers to acknowledge similarities between themselves and residents. I interacted with several quantitative health researchers who were also providers and didn't see residents solely in terms of pathology. These researcher-providers acknowledged and sometimes expressed their admiration of many residents' sense of humour and resourcefulness. Two researcher-providers told me if they were HIV positive they would also resist the daily observed administration of ARVs for the same reasons many residents gave: of not wanting to be observed taking their medication each day because it would feel demeaning. Yet, when I observed these and other health researchers at professional meetings, their references to residents usually focused on their ill health, risk for disease, the harms of drug use and the benefits of various interventions. In other words, when interacting with residents and me in the context of everyday practice, some researcher-providers acknowledged resident's vitality and similarities between their own views and residents, but when discussing residents in professional contexts, medicalized understandings of residents' difference and the value of medical interventions prevailed. The elision of similarities between researchers and residents erases *both parties'* personhood thereby reinforcing stereotypes, which are implicated in social suffering and health inequities (Kleinman & Kleinman, 1997; Ware, Wyatt & Tugenberg, 2005; Wilkinson & Pickett, 2009a, 2009b).

A third factor in the production of difference through health research is the over-reliance on a-contextual methodologies that prioritize medical aims with little attention to the history, social and structural aspects of residents' ill health. Several health researchers who conduct studies in the DTES have argued for moving beyond studies of individual behavior to examining the social context of ill health (i.e., Shannon et al., 2008; Wood et al, 2008). While some health researchers have taken up this call in general critiques of HIV risk and inequities (Larkin et al, 2007; Smye et al, 2011), as Linden et al (2012) also found, the abstracts I reviewed of health research in the DTES focussed on a few medical concerns which were identified by researchers and reflected the priorities of research institutions. I also found that the relationship between health and social factors (such as housing) were frequently limited to correlations with narrowly defined impacts for HIV care, rather than a critical illumination of how social factors, such as hunger or the low quality food that is the mainstay of free food in the area, impact health and well-being. Critics argue that 20th century epidemiology has lost its ability to illuminate social, political and economic forces of disease causation (Davey Smith & Ebrahim, 2001; Inhorn & Whittle, 2001; Krieger, 1999; O'Neil et al., 1998). These limits are attributed to a preoccupation with technology, risk, and sophisticated statistical methods (Davey Smith, 2001a; Davey Smith & Ebrahim 2001); inadequate critical reflection of epistemologies, practices and impacts (Davey Smith, 2001; Inhorn & Whittle, 2001; Krieger, 1999, 2001); and inadequate theorization about the dynamics that create ill health (Davey Smith & Ebrahim, 2001; Pearce & Davey Smith 2003; Wing, 1994). The emphasis on risk factors, which I observed in epidemiological research within the DTES, prevails in contemporary epidemiology (Krieger, 2011). This 'biomedical and lifestyle' epidemiology, Krieger (2011) argues, reflects a particular world view predicated on highly problematic casual logics that can lead to interventions which narrowly focus on addressing risks and individual behavior. This ignores the complex, dynamic interplay between historical, social and political contexts and bodies and the interacting influences of biology, asymmetries in power, psycho-social impacts of inequity, longitudinal influences through the life-course, and a multiplicity of processes which contribute to embodiment. Although the emphasis on risks and lifestyle has been effective in some areas, like the relationship between exercise and heart disease, it has also resulted in interventions which create and intensify illness (Krieger, 2011) and reinforce the (colonial) status quo.

The epidemiological research that I reviewed in this study gave no attention to the way that systemic hierarchies of race, class and gender were refracted in predictable patterns of disadvantage on the ground. The social context of residents suffering was fractured into a multiplicity of variables which were then aggregated and enumerated as P-values, confidence intervals, Cox co-efficients and so-on, and then translated into probabilities of risk. This is not unique to epidemiological research in the DTES, nor am I dismissing the need for some of this research. My point is that the overwhelming volume of such research relative to studies which meaningfully engage residents, plays an important role in manufacturing and maintaining difference. The addition of more socially oriented researchers to the complement of BC-CfE research personnel has tempered this tendency (i.e., Parashar et al, 2011), but in most cases it remains difficult to link quantitative health research to residents' lives. As one resident told me:

Yeah, statistically, more people died. I don't trust statistics too much. . . . I don't think they're accurately describing what's happening down here. They're just, all of a sudden someone's just taken notice and done a few numbers. I don't think they're anywhere close to what it's really like (Interview, 7 May 2010).

The rendering of residents' bioresources into statistics ends up representing everybody but no-body. It supports the social *imaginary* of the DTES – a place that exists in the minds of outsiders and researchers. In this way it perpetuates medicalization by directing attention to sick bodies rather than to sick societal processes, or what Farmer (2003) refers to as the pathologies of power. To reiterate, I am not negating the value of documenting disparate rates of ill health, but suggesting this work needs to be anchored in socio-historical contexts, with meaningful involvement of Indigenous Peoples (or intended subjects) and/or with processes for ensuring research is responsive and accountable to locally identified priorities. As Hacking (1986/1999) has argued, statistics are not neutral or objective but are 'part of the technology of power in the modern state' (p. 181). Statistics re-inscribe the boundary between normal and pathology, a boundary that my study shows is a prominent factor in residents' suffering. When health research is unhinged from social contexts it becomes less accountable to local needs, priorities and capacities. In the process, research becomes less about relationships and health problems *in context* and more about interests external to the community. It is one way that researchers, despite our best intentions, unwittingly perpetuate the dynamics of colonialism (Briggs, 2004; Smith, 1998; Tuck, 2009),

contributing to beliefs that ‘distort and marginalize Indigenous ways of thinking about the world’ (Turner & Simpson, 2008, p. 9).

#### **4.3.1. Intersections of health research and health service**

The distinction between health research and services becomes blurred for residents at the interface of care with implications for health care encounters. This ambiguity is reflected in the fact that many providers have led, participated in, or have been employed in health research initiatives, and that many health researchers have worked as providers in the past or concurrent with their research.<sup>33</sup> Health research often offers clinical services and health services often include research dimensions such as recruiting participants, sharing or collecting data, and having researchers observe interactions. Neoliberal reforms in health care have reduced funding for services concurrent with a growing emphasis on ‘evidence-based’ approaches (and the demand to produce this evidence), and support for research. Health research has become a vehicle to fund new programs, augment existing services, and obtain the evidence for pilot projects that, in theory at least, will enable providers to obtain ongoing funding. So while I met numerous providers who were critical of the health research industry, their concerns were often subordinated to the politics of participation and the anticipated benefits of supporting research.

Although many health researchers ‘partner’ with agencies, these partnerships are forged in discussions with agency representatives who are often providers and evaluate research projects through the lens of their professional interests and related priorities for service, with little or no input from residents. As I show in subsequent chapters, the priorities and concerns of professionals are not necessarily the same as residents. While there may be compelling reasons for providers to ‘partner’ with researchers, the nature of these partnerships, the kinds of studies they support and findings they will produce, contribute to sustaining the medicalization of residents’ lives. However, the asymmetries in power between researchers and providers cannot be overlooked. The coordinator of the Drop-in Centre shared that many health researchers had approached her in the past, and gained access to health data without any reciprocal contribution that supported the program. During fieldwork, I observed that two research ‘partnership’ which involved

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<sup>33</sup> The messiness doesn’t stop here. As discussed in Chapter 3, some front-line providers also struggled with addictions but my focus is on overlap between health research and services.

access to the Drop-in Centre's data, left the program with no control over the data once surrendered, no input into analysis, and no influence in the representation of data. Agency representatives often have limited knowledge of research methods (particularly with quantitative research), which facilitates their marginalization once research consent is obtained. In her analysis of epidemiological research among Indigenous Peoples in Northern Australia, Lea (2005) noted that the 'partnerships' between health researchers and Indigenous agencies were limited to gaining access to local data. At Native Health a research committee, formed prior to my fieldwork, ensures greater involvement of Native Health in health research and specific providers are now often listed as co-investigators. Such involvements help providers in the DTES maintain connections with wider professional networks and obtain access to related resources and benefits (such as opportunities to attend or present at conferences), which mediate the professional marginalization sometimes reported by those who work with people who use illicit drugs (Harris 2015). Some means to temper the asymmetries of power between researchers and providers was needed and at Native Health has improved the alignment between researchers, their projects and services, but does not necessarily improve the alignment of researchers' and providers' priorities with those of residents.

The interface between research and service can also influence health care encounters by surfacing moral tensions related to differences in the material realities of researchers / providers and residents' lives. Since many studies pay residents' honoraria for their participation, research represents a legitimate source of income. Yet, when providers perceived residents as motivated by 'the money' it elicited frustration and moral censure on the basis that health care should be a sufficient reward, in this way suggesting how research may negatively impact health care encounters.

In the last chapter, I discussed how providers' employment places their own economic motivations in the background, allowing them to focus on the humanitarian aims of care. As my fieldwork progressed I realized how I also foregrounded my study aims and placed the material security I derived from a research fellowship in the background, subconsciously expecting my interlocutors to do the same. My first tour led by a resident provided a memorable lesson. In my earnestness to be fair (and disregarding my supervisor's cautions), I told this resident I would pay him an hourly rate. At the end of the tour, the resident guide asked if I'd like to go for coffee and finish taking notes. I was touched by what I viewed as concern for my research needs:

[in the café] I take notes and ask him assorted questions about heroin use, the price of various drugs on the street, his family background. I suddenly notice he's looking at my watch. He has to be somewhere by 4. I say we can end our meeting now. No, he's OK and adds that he's trying to drag it out. I'm now *definite* about stopping it. I say it was about an hour. He corrects me: it was an hour and 15 minutes. I'm taken aback – he's been clocking our time! I calculate the amount. I get up, pay. . . . I feel duped and annoyed with myself. . . . and – in truth – in finding him a lot smarter than I gave him credit for. . . . I'm surprised by the intensity of my reaction – how quickly naïve sympathy shifts to taking charge (Field Notes, 15 July 2009).

The resident's behavior challenged my idealized notions of both him *and* myself. When he responded in ways that fit my desired image of myself (someone who is helpful, sympathetic, generous) and my idealized image of residents (who participated because they found the project interesting), our interaction left me feeling kindly disposed. When he responded in ways that let me see the mutual self-interest of our encounter, I was annoyed and reacted by asserting my authority. It never occurred to me at the time that he, like me, might be motivated by economic needs *and* be interested in the project. It was a response I later observed many times when providers felt their authority was threatened. Although I was studying inequities in power and was committed to treating residents with respect, I reproduced the hierarchies in power by elevating my priorities, time and moral beliefs, and by my need to control the terms of payment, assuming the resident would comply as though he had nothing better to do. These temporal, moral - *regulatory* - tendencies are not unique to health research and services in the DTES. Critiques of medical humanitarianism, discussed in Chapter 2, enabled me to see these also as culturally and professionally – *colonially* – engrained habits.

#### **4.3.2. Research-based services: Strategic and complicated**

Like residents, researchers and providers need to act strategically. Federal funding for research and programming since the 1990s has increasingly targeted 'vulnerable' populations (Murray, 2004). In applying for research grants that reinforce the link between Aboriginality and pathology, critically oriented health researchers need to decide whether the anticipated benefits of the study, in terms of service, outweigh their collusion in discourses that may contribute to perpetuating the stereotypes of residents. Privately some health researchers critiqued the local research industry while their professional activities and scholarly work appeared to support it. Similarly, I observed that several providers who were critical of the health research industry put their concerns

aside when research funding offered the chance to fund new programs or expand existing services.

The increasing interpellation of research with service is supported by the research catalogue posted on the Native Health website (updated April 2015) which listed 12 active studies at the agency when I checked it 24 June 2017, which was up from a total of two studies when I attended a Research Committee Meeting a few months after beginning fieldwork. I am not familiar with all these studies but know of a few that offered services that were welcomed by residents. A very popular 'Dudes Club' men's group, for example, was supported by an initial two-year \$270,000 research grant from a foundation devoted to reducing leading causes of death among men (Dudes Club, n.d.). Several residents in this group later contributed their bioresources to provide data for a three-year \$250,000 research grant that examined depression and suicide among Aboriginal men. The physician-lead for the group (and a co-principal investigator on related studies) has volunteered his time for bi-weekly meetings of the group for more than seven years and maintains close connections with many of the men involved (P. Gross, personal communication, 16 June 2017). Researchers have also contributed in other ways that have enhanced services. Anthropologist Dara Culhane (2011) designed and led an intensive 14-week, arts-based study *Stories and Plays* where six students worked with nine residents in telling or performing a story of their choice. Denielle Elliott, while a doctoral student in anthropology, applied her academic skills to writing two successful grant proposals for the Drop-in Centre (Elliott et al, 2015). One of these initiatives, an outreach program that aims to engage Indigenous residents living with HIV with health services, has been continually funded on a contract basis for almost 10 years.

Reflecting on researchers who have volunteered their time, written grants, participated in the Native Health Research Committee, and/or used research funding for innovative initiatives, it is clear many strive to balance research needs with an approach that tries to respect Native Health providers and residents and contribute to its services. But research-based funding for services comes with strings attached. Study protocols, consent processes, and data collection can reduce flexibility in responding to residents' concerns and insert more administrative time and paperwork into relationships. Data collection activities, combined with researchers' accountabilities to funders, also increase the monitoring and regulation of residents' lives. Yet, Culhane (2011) noted

many residents were critics of the research industry but were happy to share their experiences and perspectives when they sensed researchers were genuinely interested in their views. Many studies supported by Native Health offer clinical or socially oriented services that would not be available to residents otherwise. More broadly, however, the economic investment in research in the DTES, with some exceptions, has not led to improved funding for clinical or community-based services. And health research, has not changed the social and material conditions of residents' suffering. Given the economic and political capital invested in health research and the limited contributions to residents' lives, one can't help but ask who benefits?

#### **4.4. 'Difference', capital, and bioresources**

*[Analysis of] inequality gains credibility and efficacy when our critique addresses not only the moral but also the material bases that sustain it. (Terdiman, 2001, p. 403)*

There is no comprehensive account of the human or economic resources invested in policing, servicing and researching residents, but as noted in Chapter 2, it is clear that residents' perceived *lack of vitality* and disorder provide the bioresources that nourish multiple economies of interest (Culhane, 2003/04; Elliott, 2007, 2010).

Capital generated by and derived from health research takes many forms. For example, many providers in the DTES have achieved a level of celebrity and professional recognition by receiving awards, being featured in books, documentaries, radio and TV interviews, and newspaper articles. Several providers and media personnel have written books based on their own experiences in the DTES, with some promoting these in paid speaking engagements (i.e., Campbell et al., 2009; Lupick, 2017; Mate, 2008). While many residents have also derived economic, social and personal capital from participating in initiatives, the capital residents derive from participating in research is temporary and never enough to change asymmetries in power or improve the conditions of their lives. A key paradox of research in the DTES, as with health and other services, is that researchers and providers' position in the formal economy depends on residents' exclusion and marginalization (Culhane, 2003/04; Roe, 2009).

*Globe and Mail* reporter Robert Matas estimated \$1.4 billion was spent in the DTES between 2001 and 2010 alone, with approximately half spent on health and social

services (13 February 2009).<sup>34</sup> This fraction can be added to other fractions: in 1997, three million dollars were allocated to the area for HIV/AIDS services by BC Ministry of Health (MOH), another \$1.65 million from VRHB, plus \$5 million for HIV/AIDS drug trials from the Federal government (the latter was not specifically assigned to the DTES). These amounts can be added to the estimated \$60 million public funds spent annually on serving residents *before* 1997 (McMartin, 18 November 1997), with another \$13.9 million allocated to local priorities identified in the Vancouver Agreement in 2000 (Elliot, 2010). In 2014, two Vancouver Sun reporters identified 260 social service agencies and social housing sites within the DTES, which together, spent just under one million dollars per day (Culbert & McMartin, 2 July, 2014). A subsequent news story May 2016, reported findings of a study that found the total cost for health, social welfare and justice services delivered to 300 'high-frequency offenders' living in the area in a five year period was \$26.5 million (McMartin, 1 May, 2016).

To obtain a rough indicator of research-related capital in the DTES, in 2014 I examined abstracts of all publications listed on the BC Centre for Excellence in HIV/AIDS (BC-CfE) website that drew upon residents in the DTES. Established in 1992, the BC-CfE operates local, provincial, national and international programs of research in epidemiology, clinical virology and clinical drug-trials. I selected the BC-CfE because it is the largest health research stakeholder in the DTES and when I conducted the review, most BC-CfE research was posted on its website.<sup>35</sup> The BC-CfE website did not include conference presentations nor was it complete, as I was aware that several articles from the 1990s were missing. The majority of abstracts were based on epidemiological research, but also included abstracts based on qualitative research, studies of injection drug users in hospitals, and those that linked residents' data with similar groups at other research sites. I excluded literature reviews, position statements, virologic research, statistical modelling, and arguments for the Treatment as Prevention campaign.

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<sup>34</sup> The estimated total of \$1,468,154,865 was allocated as follows: \$717.5 million for health and social services; \$348.6 million for housing; \$154.5 million for safety and justice; \$230 million for economic development and \$16.8 for services that bridged these categories (Matas, 2009).

<sup>35</sup> Linden et al.'s (2012) review of research in the DTES from 2001 to 2011 identified 71 research publications affiliated with UBC versus 52 with the BC-CfE. It was unclear how publications by authors with joint institutional affiliations to the BC-CfE and UBC were classified. It was also unclear on the BC-CfE website because most papers have several authors with multiple institutional affiliations.

A total of 253 abstracts from 1998 to December 5, 2013 were included in my review. From 1998–2002, there was an average of 3.4 relevant article abstracts per year (range 1–7). By 2006–2013 this increased to an average of 24.9 relevant abstracts per year (range 17–34), suggesting a boom in the research industry. Of note, when I interviewed residents about the history of the epidemic, several also commented that the proliferation of research had been a relatively recent, beginning in the early 2000s. Fifty abstracts pertained to the supervised injection site (Insite) reflecting the BC-CfE’s political and professional investment in this site. ‘Aboriginality’ was addressed in 36 (14.2%) of the abstracts. Given the tendency to suppress negative findings in research (Latour, 1987) and the limited word length of abstracts, these abstracts may under-report how often Aboriginality was considered in study designs.

My research revealed the relative investments of a large number of health researchers who draw professional capital from residents’ bioresources. These abstracts reflected 265 authors; 61.2% (155) of authors were cited once and accounted for approximately 11% of all citations. Approximately 9% (23) authors were cited 11 or more times and accounted for slightly more than 65% of all citations. In later years of the period I was reviewing, I noted a marked increase in abstracts based on data from other countries, such as Uganda, South Africa, Swaziland, Mexico, India, Thailand and Australia, illustrating how the BC-CfE’s research is linked into global research networks (Elliott, 2007). The BC-CfE’s expanding interests were also evident in BC. In February 2010 the BC-CfE and BC Ministry of Health (BCMOH, 2010) announced the allocation of \$48 million to a four-year pilot study called Seek and Treat for Optimal Prevention of HIV/AIDS, more commonly known as ‘STOP’. The pilot examined the impact of aggressively testing and treating people in the DTES and Prince George, BC. The announcement for STOP followed substantial cuts in funding for community-based HIV services across the province which were announced on World AIDS Day, December 1, 2009, and were expected to cut one million dollars in VCHA alone (Sanborn, 21 December, 2009). In 2012, the BCMOH (2012a) announced that \$19.9 million was being allocated to expand the initiative to all health authorities, in support of a provincial HIV/AIDS prevention and testing policy framework (BCMOH, 2012b). STOP, a registered trademark initiative (BC-CfE, 2015), is based on the BC-CfE slogan: Treatment as Prevention for HIV (TaSP), also a registered trademark slogan (BC-CfE, 2018). The BC-CfE annual meeting for TaSP is co-hosted by the International AIDS

Society, the Joint United Nations Programme on HIV/AIDS, the World Health Organization, and the National Institute for Drug Abuse. STOP and its co-genitor TaSP exemplify the blurring of research and health services and how HIV programs can become institutions supported by influential global organizations. However, it is also more complex.

Research conducted through the BC-CfE produced the three-drug ARVs in the mid-1990s that have extended many peoples' lives in Canada and elsewhere around the world. As mentioned in Chapter 2, the humanitarian and biopolitical emphasis on saving lives presents its own challenges but there is no question that for many people, the availability of ARVs has been beneficial. Yet, the transnational economy developed around the nexus of medical research, pharma, and HIV has created new markets that have allowed many to prosper while accentuating the disparities in wealth between affluent and poor nations of the world (Biehl, 2007; Elliott, 2010; Farmer, 2003, 2006; Kim et al., 2000; Nguyen et al, 2007; Nguyen et al., 2011). This does not discount the many researchers committed to social justice, the documentation of inequities, and their desire to alleviate suffering. There are numerous publications by researchers involved with the BC-CfE that aim to influence health policy (i.e., Urban Health Research Initiative, 2009), document the social and structural barriers to residents' health (i.e., Boyd & Kerr, 2016), and improve medical services for people who use illicit drugs (i.e., British Columbia Ministry of Health & British Columbia Centre on Substance Use [BCMOH/BCCSU], 2017). But the production of research, like the production of health care, occurs in systems with their own values and forms of capital. One medical researcher I spoke with acknowledged how HIV research and pharma involved twinned globalized circuits of economic and professional capital, but observed that researchers who refused pharma funding were excluded from the arena of 'decision-makers'. In other words, the ability to conduct and use research to influence policies and services for socially marginalized people was contingent on a willingness to accept funding from pharmaceutical companies. In the social sciences, it is less common for researchers to collaborate with private industry, yet they too are constrained by structures beyond their control. For academics, tenure and promotion are contingent on maintaining an active program of research and publications.

I do not assume the industry of health care is any less complicated. In her study of public health services for Indigenous Peoples in Northern Australia, Lea (2008) found

health services self-perpetuating and ineffective. Broader and provocative questions about the investments in health research and services are raised by Dutton et al (2018). In a comparison of government spending on social and health programs from 1981 to 2011, Dutton et al (2018) found social spending remained relatively unchanged, while health spending doubled. From it, they conclude that 'population-level health outcomes could benefit from a reallocation of dollars from health to social spending, even if total government spending were left unchanged' (Dutton et al, 2018, p. E66). Such findings challenge health researches and providers who assert the need for more research or argue that more health services will improve residents' health and reduce health inequities.

#### **4.4.1. The more things change**

In late 2012, 18 months after I finished fieldwork, one of the residents I remained in contact with sent me a letter. In it he wrote:

You're not going to believe the changes that are occurring here. . . . Police have stepped up their misplaced form of justice. The Yuppies (for lack of a better word) are cursing and swearing at the addicts. . . . Now all the addicts are by the Bottle [recycling] depot and all the 'tourists' are walking on my side of the street. . . . Tonight, around 4:30, an unmarked grey cop car was driving ever so slowly down the Depot side yelling over the mic 'Move along or you will be fined', 10-15 times before he got to the end of the block and the last thing he says is 'I'm going around the block and you people had better be gone!' I watched him do this until 6:00 – probably 30 times. That was the first time they've done that (Resident, personal correspondence, 8 November 2012).<sup>36</sup>

The compounding impacts of gentrification, neoliberal reforms and economies of concern were reflected in a 2013 CBC news feature about the DTES with articles that boasted titles such as: 'Vancouver's Downtown Eastside Feeling the Gentrification Squeeze: As Development in the Neighbourhood Heats Up, Some Residents Feel Left Out in the Cold'; 'BC Struggles to Treat Severely Mentally Ill Drug-Addicts: Mental Health Crisis Looms as Emergency Services Face More Violence on Vancouver Streets'; 'Mental Health Crisis Getting Worse, Says Vancouver Mayor: 21% of All Vancouver Police Calls Involve a Person with Apparent Mental Health Disorder' (CBC, 27

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<sup>36</sup> The collaborative nature of my study meant that research would not be complete until participants had an opportunity to discuss and comment on my findings. As explained in Chapter 3, I maintained contact with many residents after I relocated to Victoria, BC.

December 2013). The DTES continues to be characterized as a problem place, occupied by problem people.

The category of the 'Mentally Ill Addict' (MIA) gained traction as new object of concern, dressed in familiar tropes of its danger to society. Boyd and Kerr (2016) linked concerns with MIAs' to a series of Vancouver Police Department (VPD) reports between 2008 to 2013 which advocate for a re-institutionalization of MIA and an increase in resources for policing in the DTES. The move carried shades of the VPD-led Citywide Enforcement Team in 2003 which tripled the number of police officers in a crackdown on crime that targeted residents of the DTES. The crackdown, which arrested 90 individuals in the first five days, preceded a bid for a \$2.3 million increase in funding (Eby, 2006). The figure of the MIA was emerging at the same time residents were telling me that police harassment was making them reluctant to leave their buildings, and as newer buildings were offering in-house programs giving residents more reasons to stay inside.

Then in 2016, deaths from suspected fentanyl overdoses rose dramatically in BC, as in many cities across North America, from 993 in 2016 to 1,422 in 2017 (Ministry of Public Safety & Solicitor General, 31 January 2018). The number of illicit drug overdoses in BC for 2017 was 3.5 times the peak of 400 drug overdoses in 1998 (Ministry of Public Safety & Solicitor General, 31 January 2018), and triple the peak of 331 HIV/AIDS deaths in 1994 (British Columbia Vital Statistics Agency, n.d.). After years of deliberation about the supervised injection site in the DTES, there has been a rapid expansion in supervised injection sites in Vancouver, Surrey, Victoria, and smaller communities, and rapid changes in policy. Physicians are now able to prescribe opiates to individuals who have not found methadone or other drug treatments ineffective. At the same time medical practice has expanded in some areas, it has been curtailed in others. The College of Physicians and Surgeons and the College of Pharmacists introduced stringent provincial guidelines in June 2016 for the prescription of opioids. The impact of these guidelines for those no longer able to obtain opioids from physicians has not yet been documented by researchers. Visiting the DTES in June 2018, several residents told me that as more physicians with-hold prescription opioids, those with chronic pain are compelled to purchase fentanyl on the street to obtain pain relief which increases their risks of an overdose: a problem which is starting to gain media attention (Bains, 25 June, 2017).

Another change in response to the fentanyl crisis, has been the development of the Provincial Guidelines for Biophyscosocialspiritual Withdrawal Management Services (BC Ministry of Health, 2017). Core principles informing these guidelines are accessibility, respect, personhood and an emphasis on peoples' strengths. How these principles will translate into services and health care relationships on the ground is currently unknown. In many respects, however, the deployment of colonial tropes in the representations of residents continues. Experts inside and outside the area still speak for residents without hesitation. Residents are constructed as dangerous, disorderly and, with the fentanyl crisis, in need of services, management and supervision rather than being seen as self-determining citizens.

#### **4.5. Conclusion: What difference does 'difference' make?**

In this chapter, I have described how the DTES and various groups of residents have been defined by disorder, immorality and disease at various points in time. I contend that the processes entailed with constructing the area and its residents as social problems have their genesis in colonization and representations of Indigenous Peoples. A convergence of forces around the HIV epidemic in the late 1980s and 1990s gave rise to a particular reiteration of the colonial Savage in the figure of the Addict. My emphasis in this chapter has been on examining how the local health research industry contributed to constructing the Addict by reinforcing the link between Aboriginality, drug use and pathology. I explored the professional and economic capital generated by researching and treating residents' suffering and argued that health research is part of a broader institutional apparatus that re-enacts the colonization of Indigenous Peoples' lands at the level of residents' bodies. Most health research claims to have Indigenous Peoples'/residents' 'best interests' at heart but does not attend to subjects' perspectives or priorities and thus ends up reinforcing inequities by protecting the economic, political and professional interests of those with power. Neoliberal reforms have resulted in health research becoming more entangled with practice and an avenue to support new or existing services.

In examining published health research in the DTES, I found that the over-riding emphasis was on *describing* differential patterns of risk. Health researchers, like providers, have diverse interests and perspectives but the colonial dynamics that inform

these fields of endeavour become visible in their shared emphasis on residents' pathology, the assumed value of health sciences and need for professional intervention. The economic and professional capital associated with health research and services, rely on residents' pathology and bioresources for their survival. In the process, residents' personhood, analysis and social realities are rendered invisible, or are subordinated to those of health researchers and providers. On this basis, I contend that the health research and service industries, as two of the many industries of concern in the DTES, re-enact geopolitical processes of colonization dispossession at the level of residents' bodies, reinforcing colonial dynamics and inequities, and contributing to residents' ongoing marginalization.

## Chapter 5. Residents' critiques of health services

Providers' perspective on their helping role was often at odds with residents' experiences of their care. This disjuncture in perspectives wasn't unique to providers and was also reported in relation to many researchers, including myself. For example, frustrated by my concern one day, a resident said to me, 'you think you're different [from providers], but you're not – you're just like them!' (Field Note, 13, April 2011). In the effort to counter residents' negative experiences with authorities it was often difficult for providers to consider how residents' experiences with authorities (good and bad) could blur together. Once, amid a boisterous reunion with another resident, she suddenly pulled back remembering she hadn't yet taken her ARVs. Seeing me, she explained, always reminded her of 'authorities' even though I had never reminded or coaxed her to take her ARVs, nor questioned her decision to stop taking them for various periods of time.

When I asked residents to describe their *general* experiences of health care, they emphasized the challenges which positioned positive relationships with providers as exceptions. The emphasis on negative experiences can be explained by several factors. Even when residents had positive relationships with specific providers, they typically interacted with multiple providers when accessing care. This, and residents' cumulative experiences with authorities– which were usually negative – influenced the overall impression of the care they received and how they approached new encounters. As discussed in Chapter 2, Samson (2003) found that, although there may be no direct connection between government institutions, similarities in their colonial dynamics, in terms of the beliefs about Indigenous Peoples, rationalities and responses, often left Innu with an impression of a common institutional front working against them.

While differences in the material foundations of residents' and providers' lives is an important determinant of their social in/stability, I contend in this and later chapters that residents' patronage is critical to sustaining the (relative) stability and vitality of health services. By the need for relational and flexible approaches to engage many residents in care, residents' personhood also indirectly contributed to the humanization of service delivery for providers across Native Health. Despite providers' desire to help, residents' critiques of care illustrate how the colonial dynamics of care can accentuate

the instabilities of their lives. Although health providers frequently talk about residents' marginalization, when fieldwork was centred outside of the Vancouver Native Health Society (Native Health) and in the midst of residents' daily routines and activities, like spending time with friends or their efforts to make money. From this I saw how health services were often peripheral amid the whole of residents' lives. Even when a resident has a close attachment with an individual provider, positive interactions tend to be brief and episodic relative to the resident's broader exposure to surveillance, regulation and inequities, and the activities and relationships of their lives. Together, these demonstrate the limits in and impermanence of positive health care relationships and the potential contribution of these to the social instabilities of residents' lives.

Rather than focussing on the difficulties associated with being poor or using drugs, reading residents' critiques as critiques of colonization draws attention to systemic processes that preferentially support the interests of some groups at the expense of others. Just as colonial tropes of Aboriginality negated the diversity and personhood of Indigenous Peoples, I argue in this and subsequent chapters that beliefs about Addicts, which are systemic, encoded in the colonial dynamics of health care, and often communicated through providers' practices, often leave residents feeling objectified and dehumanized. Just as colonial beliefs about the benevolence of state interventions justified the colonial dispossession of Indigenous Peoples' lands, the governance of their lives and generated the disparities in wealth, beliefs about Addicts enact similar processes in health care. The enduring inequities of residents' lives draws attention to the fact that providers derive the greatest economic benefits from health care, which helps understand how residents come to understand their bodies and suffering as economic resources that are exploited by others.

I analyse residents' critiques in four sections. The first section addresses their critique that health services 'try to control you'. I begin by mapping the broader context with attention to police surveillance, the daily rounds made to agencies for food, the realities of homelessness and housing, and health care. I then discuss the regulatory nature of health care in more detail and how residents' awareness of their reliance on services, combined with asymmetries in power, influenced their responses to providers. I conclude by discussing the processes and impacts of 'banning', a disciplinary practice and form of spatial dispossession which involved providers barring residents from

services for periods of time in response to their misconduct. In some instances residents were banned from services for life.

In the second section, I discuss residents' critique that providers 'treat you like an Addict' and discuss how residents also deployed the figure of the Addict to deflect scrutiny of their behavior or to assert their personhood and cultivate relationships with providers.

In the third section, I address the critique that 'they're just in it for the money', which points to the economic benefits providers derive from assisting residents. I argue that the economic reliance of health services on residents' bioresources and the blurring of medical practice and medical research reinforce residents' experiences of colonial inequities, exploitation and awareness of their bodies as economic resources.

Residents' critiques of health services co-exist with awareness of their reliance on providers and the importance of maintaining positive relationships. Many residents depended on providers to support their applications for social benefits and housing and for help with other matters, such as child custody, criminal charges, character references for employment and housing, access to adjunct supports, and buffering their relationships with other providers. While HIV infection brought many residents into contact with health services, as supportive relationships developed, providers' assistance with nonmedical concerns and affirmation of residents' personhood could become as important as medical care. In the final section of this chapter I consider how residents engaged in health work to manage the asymmetries and complexities of care in an effort to get their needs met.

## **5.1. Regulation: The everyday life of residents**

*There's lineups for everything! . . . You're running from here, you're running from there, you're running from one line to another line and your day is done. And you're beat. You're wore out, you're frustrated . . . and then if people snap [at you] . . . it gets you pissed off . . . it's a hard thing right? . . . [E]ventually it starts to break you down. (Resident, Interview, 5 February 2010)*

In my interviews with providers, many recognized that negative experiences with authorities often caused residents to mistrust health providers. Several providers also

acknowledged the stress of residents' lives in terms of inadequate housing, the activities entailed in sustaining their drug use, and their exposures to violence and exploitation. The translation of this awareness into practice was another matter as most residents felt providers had little understanding about their everyday lives and did not recognize the strengths entailed with survival.

Providers recognized the historical and social context of residents' lives by emphasizing the cultivation of trust, the need to suspend judgement and expectations for rapid change, and the importance of creating a positive experience of health care. However, providers' efforts in these areas were often limited by many factors such as constraints on their time, not seeing the relevance of contextual information to residents health concerns or treatment plans, not recognizing the moral dynamics of care, and how residents' priorities and their understandings of health concerns might be different.

Residents' suspicion toward providers and their critique, 'the try to control you' is better understood in the context of the extensive regulation of their daily activities. Here I highlight four prominent examples of this regulation: police surveillance, the daily rounds of visiting agencies for food, the challenges of homelessness and housing, and visits to obtain health care.

### ***Police surveillance***

During fieldwork I spent many hours at different times of the day casually interacting with residents or observing them on the 100 block of East Hastings Street. Every half hour or so police trolled the block. Walking two or three abreast, police enforced laws against drug-trafficking, panhandling, loitering, selling items on sidewalks, jaywalking and sleeping outdoors. At any time, residents could be stopped, have their bodies and possessions searched and have their identities checked against police records. It was not unusual to see residents pressed against the sidewalk, buildings or police cars with their arms held behind their backs in handcuffs. One frail Indigenous woman reported having her bag checked three times in one day. Some residents' said police had become 'more professional' the last 10–15 years. Others said the violence was only more concealed. I also witnessed two incidents of residents being assaulted by police in the middle of the day in full view of traffic and pedestrians on Hastings Street. The first received national media attention when it was caught by the surveillance camera outside a housing agency. The offending officer was suspended for six days. In

the second incident an Indigenous youth was assaulted when an officer overheard and personalized a joke the youth intended for his girlfriend. The youth and witnesses in this instance were unwilling to be identified in the formal complaint I submitted. On investigation, the assaulting officer was believed to have used reasonable force.

Whether police have become more professional or whether harassment has become more concealed, all residents agreed police harassment continued and several residents reported receiving severe beatings from police. Having a criminal record drew added scrutiny. Surveillance on the beat was augmented with cars and cameras positioned over many public spaces. Just like those incarcerated in Bentham's panopticon (Foucault, 1975/1995), residents were ever alert to the potential of being watched. Interviews were often interrupted as residents noted police or 'undercovers' in proximity or caught the reflections of police in mirrors or windows.

### ***The rounds***

*You got your government welfare services, you got your health people, then you got your housing. So, you combine all these together and then you got all these little run arounds, like standing in lines here – it's almost like you're a little robot. (Resident, Interview, 9 December 2009)*

Many residents had regular routines for visiting agencies to obtain food and could describe where better meals were offered over the course of the week and month. One resident, 'Bob' agreed to let me join his morning rounds at 6:30 a.m. one day and I documented his morning rounds as follows:

At the first stop [a faith-based drop-in centre], coffee is dripping through the filter and a bowl of pastries cut in half sits on the counter. People come and go, some sit on chairs sipping coffee, chatting with staff. . . . An older man approaches asking if I'm ready to receive Jesus Christ as my personal savior. . . . Bob asks staff if they know of any 'surveys' [researchers who might be seeking research subjects]. No. . . . At the second stop [a restaurant catering to residents], we join another line. . . . The lineup starts to move after 10 minutes. . . . We walk in the back door of the agency, past a cafeteria counter where we're handed a styrofoam cup of gelatinous macaroni soup and a bun. . . . Bob drinks half, throwing the rest in the garbage as we exit. He says he rarely finishes the soup but it helps fill the hole. . . . At the third stop [an Indigenous run drop-in centre], coffee, tea and cookies are placed on the counter – people enter, help themselves and leave. Staff don't allow residents to use the washroom here. . . . At the next stop [a faith-based shelter], the line-up is so long we don't wait. [Bob informs me that] once a month before welfare Weds., [this site] serves sausage and eggs. We conclude the tour at [the Drop-in

Centre] in time for lunch at 11:30. Awake since 5:30, the resident has eaten two halves of a sweet-bun, half a cup of soup and several cups of coffee. (Field Notes, 22 June 2010).

In a given month Bob's daily rounds were punctuated by participation in agency programs, attending meetings at another agency where he sat on the board, medical appointments and follow-up (blood work, prescription renewals, etc.), and meetings with researchers. Beyond getting food, the morning rounds lent a sense of structure to his days and provided an opportunity to socialize with other residents and staff. Maintaining relationships with providers in several agencies also helped him stay abreast of opportunities for new research surveys, projects and programs that offered honoraria.

### ***Housing***

Although residents' and providers' perspectives differed on many things, they agreed about the critical relationship between stable housing, health and well-being. Several residents reported that sleeping outside had become more dangerous over the last 20 years due to increasing violence, enclosures of public spaces, and the intensification of surveillance by police who forced residents to move every one to two hours and sometimes issued fines. Some residents reported trying to stay awake at night and sleep during the day, but many agencies prohibited residents sleeping on site due to fears they might not detect an overdose. Only one shelter in the DTES, First United Church, was open 24 hours a day. However, having a roof over one's head came with other challenges. An Indigenous resident told me that in some shelters run by religious organizations:

You have to sit there and be forced to listen to somebody preaching . . . just to get a meal. Or [before] you go to sleep . . . you gotta sit there and listen to them read their scriptures. . . . I don't think a person should be forced to do that (Interview, 5 February 2010).

Shelters known as 'mat-programs' placed sleeping mats on the floor, which cramped one's personal space. The resident continued,

You can't even reach your arm out and you got somebody right beside you . . . and then you got that person snoring in your ear and you're trying to sleep . . . and you got people farting in there, and talking in their sleep, and then you got a light on all the time so they can walk around (Interview, 5 February 2010).

Shelters often contained many residents with mental illnesses, which could be stressful for others. Co-ed shelters carried heightened risks of assault for women and transgendered residents. Common bathrooms in one shelter were described as unsupervised injection sites. At least one shelter had a blue-light in the bathroom which made it very difficult for people to inject drugs. But the poor light also meant that some residents missed toilets and urinals and soiled the floor. 'You learn', one resident said, to 'never take your shoes off in the bathroom' (Interview, 15 March, 2011).

There was one agency where homeless residents could get their laundry done, but they had to pick it up by a certain time. Failing to collect one's laundry by the appointed time resulted in it being thrown out. If the time to collect laundry coincided with the time to start lining up to get a shelter bed, 'you gotta choose which is more important, the bed for the night or the laundry. . . . I got make sure I have a place first – that's more important to me than a bag of clothes' (Interview, 5 February 2010).

Single room occupancy hotels, or SROs, have historically housed the large number of single adults living in the area. These rooms typically have sinks, hotplates, shared bathrooms and, in some cases, shared kitchen facilities. SROs tend to have fewer restrictions than subsidized housing units, but greater freedom comes at a cost. For example, SROs allowed couples to share rooms and didn't prohibit overnight guests, but several women who had lived in SROs recalled living in fear that the door of their room would be kicked in. More than one woman told me about waking up at night to find strange men in their rooms. A longstanding lack of maintenance and enforcement of building codes had allowed many SROs to slip into states of gross disrepair with elevators not working, problems with plumbing and running water, infestations, and a lack of functional locks on rooms. Subsidized housing units tended to have better rooms and maintenance with access to onsite staff if problems arose. However, some also prohibited couples from sharing rooms and restricted overnight visitors. All the subsidized housing units I knew of had surveillance cameras in all public spaces, such as entrances, hallways, elevators, and meeting and laundry rooms. Although residents resented the regulation of their lives, several in this study who lived in these buildings found that the security systems improved their feelings of safety, helping them to moderate visitors, and keep drug-dealers and other residents outside the building at a distance. Getting into these units usually involved being on wait-lists for over a year.

The struggles of one resident to get out of a shelter and into an apartment were a testament to his endurance and self-control. He met resistance from landlords at each of the 30 apartments he reported visiting in one week. He then tried institutional channels, starting with BC Housing. Finding himself on lists to get into various buildings with wait times of eight months or longer, he enlisted the help of staff in two agencies to increase the chance of getting results. A succession of meetings with staff, which entailed a host of personal questions,<sup>37</sup> led to the submission of applications to numerous housing agencies but brought him no closer to an apartment. Demoralized and desperate after several months in shelters, he persuaded a friend to share an apartment. The friend brought people home at all hours of the night and then fell short on rent. Unable to meet the payments, he became homeless again. The only option for a private apartment was to surrender to the lengthy processes of housing agencies. After being on a wait-list for over a year, he finally secured a one-bedroom apartment in a bed-bug infested building in the 100 block of East Hastings – the very same building two other residents I knew had been equally desperate to leave.

Thinking the challenges were, in part, a result of agency staff having inadequate time to assist residents, I offered to help another resident get out of his noisy, bed-bug infested building. I set off optimistic and confident in my ability to navigate systems, but just as residents had reported, I immediately encountered bureaucratic walls. The challenges of getting information, combined with the lack of consistency and coordination between housing agencies made it virtually impossible for residents or someone like me, who was unfamiliar with the processes, to obtain housing independently. Some housing staff were sympathetic to residents' plight, but were powerless to do anything since the need for housing overwhelmed the supply. The labyrinthine system taxed my optimism and endurance to the point where I, too, felt defeated and demoralized. My effort to help the resident brought him no closer to an apartment and only underscored my own hubris in believing that I would be more successful.

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<sup>37</sup> Questions explored intimate details of one's health, personal relationships and background. During one interview that I observed, the official obtained information required by the application form but apologized several times for the intrusiveness of questions. The rigor entailed in assessing the resident's suitability was at odds with the disrepair of many SROs and, by the official's own admission, several of the buildings her agency managed.

### **5.1.2. Regulation and health care: ‘They try to control you’**

For many residents the daily rounds included visits to health care facilities for prescription renewals, blood work, and applications for financial subsidies, housing or other social services. The governance of residents was encoded in space, regulations and treatments. Entering agencies, residents re-entered a moral order of a social world that, for many, was associated with judgement, failure, rejection and harm. The inequities between residents’ and providers’ worlds were symbolized by the locking and unlocking of doors. Regardless of weather, residents waited outside until doors opened, while staff had meetings, caught up on paper work, or prepared for service inside.

Some providers were mobile and any place they went was potentially transformed into a clinical space (Patton, 2010a, 2010b). Outreach was often appreciated but at other times was experienced as an intrusion. Viewing public and domestic spaces as ‘private’, many residents preferred to confine health interactions to agency settings. One resident reported being approached by providers while drinking in a park with friends. When the providers asked about an embarrassing health matter, the resident was livid: she, not providers, was responsible for her health and she knew where to go if she had concerns. Being singled out in public by an authority was experienced by another Indigenous resident as exclusionary. ‘It’s not right. When they’re out here they should talk with everybody, make them feel good’ (Interview, 28 December, 2009). Seeing an authority interact with residents often elicited the interest of onlookers in whether the resident was working with undercovers (police) or had a warrant out for their arrest. After speaking with me in public, several residents reported being approached by onlookers asking who I was and what I was talking to them about.

#### ***Appointments, referrals and ‘bad news people’***

Some residents avoided health care because it often marked the beginning of time-consuming medical investigations, follow-up appointments and referrals. Because providers focussed on the benefits derived from health care, many had difficulty understanding the stress, fears and inconveniences involved in receiving care and how these were compounded by residents’ interactions with other services. It wasn’t that residents discounted the benefits of health care or of referrals, but when residents wanted the service, they were often frustrated by numerous additional complications, related impacts on their time, lives and other commitments.

Drawing from my field notes, the follow-up for one resident referred to a psychiatrist involved: stopping at the front-desk and making an appointment to see the Clinic nurse before leaving the Clinic; travelling home and back to the Clinic for the appointment with the Clinic nurse (the resident lived outside the area); seeing the intake person, waiting to see the nurse, seeing the nurse to get the appointment with the psychiatrist, and travelling home; travelling back to the Clinic on the date of the psychiatrist's appointment, seeing the intake person, waiting in reception, seeing the psychiatrist, visiting the pharmacy, waiting for the prescription, and travelling home.

Receiving a referral left many residents feeling brushed off and rejected. Providers' emphasis on matching health concerns with the corresponding areas of expertise reflected a professional obligation to recognize the limitations of their knowledge and skills. It was not that residents necessarily discounted the value of specialists' attention, but they tended to express personal concerns with the provider they felt the most comfortable with. Their experience of a relationship, not abstract knowledge or skills, was often integral to the medicine they were seeking. Furthermore, the benefit of a specialty service for a health concern could be outweighed by the stress, uncertainty, fear of judgement, or anticipated discomfort of seeing someone they didn't know. The disincentives to accessing care were impressed upon me one evening when a resident called and asked if I had any eye drops I could share with him. While helping someone with a construction project that day, he suddenly noticed there was something in one eye and was now struggling to open it. He did not want to see a physician at Native Health lest it get back to the Drop-in Centre where staff might require him to take time off from his volunteer work. However, he agreed to let me take him to a hospital emergency department. On exam, the physician noticed a small object in his eye and directed him to see an ophthalmologist the next day. Even though there were two ophthalmologists' offices close to his home, he never followed up. That he would risk compromising his vision rather than visit a specialist was a testament to the powerful and complex forces that impede access to health care services.

The experience of follow-up and referrals compounded residents' experiences of institutional regulation and the risks and fears associated with medical care. When many residents were already struggling to cope and believed there was little reason to expect a better future, health care was not necessarily linked to well-being but to the

expectation of further problems and stress. As one resident explained, providers were 'bad news people' (Interview, 5 February, 2010).

### ***'Rules, rules rules'***

'If you had all the power' I asked one resident, 'what is one thing you'd change about health care services?' Without skipping a beat, she replied:

Just the whole rules, rules, rules stuff. Like barring people and cutting them off and ostracizing them and punishing them for being who they are, for being what they are. It's like being angry with someone for having cancer! (Interview, 1 September 2009).

Residents both resented and relied on regulation. While residents saw rules as necessary for unruly counterparts, when subjected to regulations themselves they usually resented it and felt it was unjustified. The critique of regulation often concerned the manner in which the rules were communicated and enforced. Providers who elicited the most complaints were those who prioritized conformity with regulations; those that residents described as acting 'like cops', tended to be male, and those who left them feeling treated 'like a kid', who could be male or female.

Focussing on a particular interaction or setting, one can lose sight of the multiplicity of rules that surround residents' lives and constrain their freedom (Frye, 1983). The surfeit of regulations left some residents likening life in the DTES to being in prison. Agency-wide rules commonly included no fighting, no swearing, no discriminatory remarks, and no drugs, alcohol or weapons within the agency. Anyone who was obviously high or drunk could be barred access. There were also site-specific rules, such as not being able to obtain prescriptions for opiates from the Clinic on weekends. Several programs also had their own rules. The methadone program, for example, required regular urine screens, attending the pharmacy daily for observed ingestion, and obtaining medical permission for 'carries'.<sup>38</sup> Some rules were formalized in writing and posted on walls while others were informal and only communicated verbally, such as the need to avoid criticizing services. Other rules were ad-hoc, created in response to particular situations. With the exception of rules imposed by laws and external regulatory bodies (such as those associated with the prescription of regulated drugs), the power to

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<sup>38</sup> 'Carries' refer to medications that are usually dispensed daily from pharmacies but in extenuating circumstances (such as travelling to visit family) will be dispensed for longer periods of time.

make, enforce and change rules lay in the domain of providers and agencies. The feeling of over-regulation was not just a response to one provider's enactment of rules, but to the number of providers residents interacted within one setting. This regulatory potential within a health care setting was compounded by the regulations of all the other authorities that interfaced with residents' lives outside the setting.

Residents explained the disciplinary tendencies of health services in various ways: providers' inability to see residents as people with feelings; providers' lack of understanding about the experience of addiction and the stresses in residents' lives; providers' contempt and fear of residents; providers' need for power and control; and the belief, in one case, that the provider derived sadistic pleasure from disciplining residents.

### ***Banning***

The disciplinary side of health services crystallized in the practice of banning. There were many reasons for banning such as physical fights, theft, threats of violence, and racist remarks. The interpretation of infractions deemed serious enough to warrant banning and the type of sanctions imposed varied among providers. While several providers opposed the practice, the Clinic and the Drop-in Centre continued to ban residents for violating various regulations. Once banned, residents were unable to access services for periods ranging from one day to life. Having witnessed the intensity of one resident's demeanour following a conflict in the Clinic, I did not doubt the need for measures to ensure providers' and other patients' safety. However, if residents' responses could be frightening to providers, it was also true that the intensity of some providers' demeanour could be frightening for residents. As discussed in Chapter 6, when providers' behavior reminded residents of an authority figure who had harmed them in the past, it could unleash a response where emotions associated with past harms fused with the present.

From 1998 to 2007, an average of 12 residents were banned from the Clinic annually, but in recent years the number ranged from zero to three (Source, T. Braun, n.d.). Providers suggested that several factors influenced the decline in banning: residents' socialization to agency norms, growing discomfort with the practice among providers, and greater use of street drugs than alcohol. Several providers who had worked at Native Health for many years said that in the late 1990s more residents accessed services while drunk, which contributed to many fights. One provider likened

the atmosphere within agencies at the time to a 'wild west saloon'. The complement of physicians and Clinic leadership was also a factor. Two providers speculated that a certain physician, who no longer worked at Native Health, felt more vulnerable with residents and had a greater tendency to enact bans. All of these factors may have contributed, but I noticed that the arrival of a new physician clinic coordinator in 2006 coincided with a refinement in the process and a noticeable reduction in the number of residents banned. Since then all serious behavioral infractions were reviewed by the clinic coordinator before a ban was imposed. There was no formal record of residents banned from the Drop-in Centre but throughout fieldwork it was not uncommon to hear of residents being banned for days or weeks. According to a resident-volunteer overseeing reception, the total number of residents banned for life was less than five.

I interviewed seven residents about the circumstances and their experiences of banning. A few residents acknowledged their culpability saying they had been 'an ass' (Interview, 17 July, 2010) or 'got rude too many times when I was high' (Interview, 27 May, 2010). In some cases, residents were allowed back after a designated period of time. In other instances, reinstatement required residents to meet with counsellors or physicians, write letters of apology, sign behavioral contracts and/or, in exceptional cases, obtain the executive director's approval. The need for services pressed some residents to adopt the official (provider) view and see the incident as their own fault. However, when the Indigenous resident who 'got rude too many times' explained the context surrounding his behavior, culpability became less clear: 'they tried to enforce everything on you . . . I don't like being bossed around and told what I can do and what I can't do, and what I can say and what I can't say' (Interview, 27 May, 2010). No one disputed that residents could behave poorly at times, but providers could also be rude, authoritarian and aggressive when interacting with residents.

For most residents, responses to banning mingled feelings of anger, humiliation, injustice and loss. Those who felt they had done nothing wrong were embittered. Recalling the experience, even years after the incident, still evoked strong emotion among some residents. For two residents, banishment from the Drop-in Centre signified multiple losses: the loss of social contact and community among others living with HIV; the loss of structure and purpose for their day; and the loss of access to the food-bank, meals and other supports. One resident said banning precipitated painful memories associated with being 'kicked out' of his home as a youth and left him despondent and

reluctant to leave his apartment for two weeks. Another resident submitted the required letter of apology, but weeks, months and years passed without any acknowledgement. He could not bring himself to approach the Drop-in Centre again. The pain of banishment was compounded by the pain of being forgotten.

The biggest residual complaint residents had of banning was not having a chance to tell 'their side of the story'. Banning ignored the intersubjective dimensions of conflict and did not include any process to consider joint accountability. Residents not only carried the blame but paid for it in the loss of services while providers continued to work. For residents, banning exemplified inequities as they bore the humiliation of public discipline while, with the exception of several instances in the Drop-in Centre, providers were disciplined in private.

## **5.2. Judgement: 'They treat you like an addict'**

Residents' second major critique of health services referred to the judgement and dehumanization of 'being treated like an Addict'. This critique is complicated by the fact that some residents also deployed the Addict to deflect attention from their behavior, to gain visibility as persons and to maintain positions of privilege. In addition, the definition of the Addict, as constructed in health research and as enacted in providers' practices contrasted greatly with many residents' understandings of what it meant to *be* an addict.

Where health researchers emphasized Aboriginality in local studies about drug use and HIV, I found that it was the Addict rather than the Aboriginal which held valence in residents' everyday lives and providers' practices. Connotations of the Addict (as in being treated *like* an Addict) were not the same as residents' understandings of addiction, just as the meanings of Aboriginality in health literature were not the same as the diversity in Indigenous residents' understandings and lived experiences of being Indigenous.

### **5.2.1. Treated like an Addict**

Most residents reported being 'treated like an Addict' in the context of relationships with authorities and described it as feeling stripped of one's history, personhood, worth and strength in having survived hardships. For some, it reinforced

self-recrimination: 'I'm really pissed off at myself', one Indigenous resident explained, 'because I'm in that category; it's my anger toward myself mostly because I have a choice and sometimes I don't make the right choice' (Interview, 4 April 2011). On the street where addiction was part of everyday life, residents faced discrimination from counterparts for their HIV infection. Inside health agencies where HIV was accepted and routinized in treatment, residents encountered discrimination for their addiction. Since health services were there to help them, feeling judged for their use of drugs heightened the sense of exile.

The Addict signified overlapping social categories and the associated dehumanizing impacts of social discrimination. As one Indigenous resident explained, it's 'like you're a criminal, you're a drug addict, you're a hooker, you're a drug dealer, or you're homeless . . . pretty soon you can just be a statistic' (Interview, 13 April, 2010). For some, 'being a number' was the ultimate erasure of their personhood and was a common feature of bureaucratized care: 'when you access services you have to be a number, you are always a number' (Field Notes, 12 November 2009). The experience of objectification was conveyed in the selective in/visibility of their bodies and lives to providers. One resident had found:

Some staff, they just want a yes/no and get on to the next question it seems. You can tell when you're being rushed through a conversation or when they're actually interested and want to know what's going on with your life. . . . And then they approach you later and all of a sudden they're 100% attentive but only about their subject though . . . you don't even want to have any interaction with them (Interview, 7 June 2010).

Being treated like an Addict was often synonymous with feeling treated 'like a kid'. Infantilization was not unique to the DTES (O'Neil, 1989; Paine, 1977), but gained added intensity there through the concentration of services and prevailing beliefs about residents' vulnerability. As one resident told me,

If you miss appointments, they ostracize you and make you feel like a child. It's just, they talk down to you and you just don't get that same respect and patience and perseverance that they would have with other patients – they don't have that with Addicts (Interview, 1 September 2009).

Paternalism was naturalized in health care where providers saw their roles as benevolent and acting in patients' best interests. Several providers likened their

relationships with residents to that between a parent and child, making it more accurate to talk about 'parentalism'. I noticed this most with female providers. For example, one female provider mentioned scolding residents 'just like I do with my kids' (Interview, 10 November, 2009). Another referred to herself as 'mommy' when interacting with residents, and a few providers referred to female residents as 'sweetie', 'dear', or 'honey'. Many residents recoiled from such terms but there were also those who saw them as expressions of care. Parentalism was infrequently observed among male providers, but it was possible they were less overt in their expression.<sup>39</sup>

Male residents were the most vocal in their critiques of being 'treated like a kid'. The masculine culture of street life emphasized independence and self-reliance. Being a man meant not whining about one's difficulties and cultivating respect by 'taking no shit'. Failure to stand one's ground against insults marked one as weak and a target for exploitation. Yet, on entering agencies, residents were required to be cooperative, patient, describe their concerns in detail, and submit to the direction of providers – behaviors that signified weakness in street life. In the public spaces of agencies, such behaviors could compromise one's social status among counterparts and make them a target for victimization on the street.

Feeling 'treated like an Addict' spoke to a paradox identified by other researchers: residents' suffering was the public face of the DTES, yet in everyday interactions with providers, residents often felt their lives and humanity were invisible (Culhane, 2003; Robertson & Culhane, 2005). Inequity and invisibility were evident in the differential attention given to celebrate providers' awards and departures versus those of residents. A memorial held for a respected provider who passed away was criticized by several residents who said it showed whose lives were seen as more important as many of their counterparts had passed away without comment. One resident with close attachments to the worker was never notified. I knew there was no conscious effort to exclude the resident, but the point is that residents' who had relationships with the worker weren't considered. On hearing residents' criticisms of the worker's memorial, a

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<sup>39</sup> When speaking with a male physician about my evaluation of the PSMS study, I mentioned that the Drop-in Centre offered stability that enabled resident-coaches to stay involved in the study. The physician then suggested that organizationally the Drop-in Centre was like the mother and the Clinic was like the father in the respective functions they filled for residents' involvement in the project. The structural dyad of parental roles, the gendered assumptions and the analogies for service this implied, positioned residents as children.

new coordinator of the Drop-in Centre started organizing monthly memorials for residents who passed away but few, if any, residents attended. It highlighted the asymmetries in accountability and was something I also observed in some of my relationships with residents: that when providers' adjusted services in response to residents' critiques, there was often little or no follow through from residents. While several reasons could be offered, such instances highlighted the complexities of care for providers who *did* take residents' perspectives seriously. Efforts to understand residents' *lack* of response, encouraged providers' to prioritize the influence of residents' drug-use and social realities, thereby accentuating beliefs about their vulnerability and disorder, drawing attention to the challenge of respecting residents' critiques while needing to suspend expectations for their responses.

For all residents, feeling 'treated like an Addict' was fundamentally an issue of justice. As one Indigenous resident said, 'These people down here, they're screwed up and everything, but they're humans too. They got a right to be treated equally' (Interview, 8 April 2010), or another who explained: 'You feel like you're being judged by somebody that doesn't know where you come from, what you've been through, what you have to deal with on a daily basis . . . by somebody that has *no right* to do that' (Interview, 21 April 2011).

Residents resented being treated like Addicts, but they did not necessarily disagree with the behaviors imputed to Addicts. Time and again residents told me, 'you can't trust anyone in the DTES' and relayed stories about getting 'scammed' or 'ripped off' by counterparts. When it came to their own behavior, a different set of rationalities came into play. Residents explained their actions in terms of self-preservation, survival, 'the game of street life', retaliation, or as acts of rebellion against 'The Man'. The issue of residents lying, identified by both providers and residents, intrigued me. People lied, one resident explained, because they didn't want the provider to know what they were 'really like' lest it change the provider's support and regard for them. Yet when residents tried to cover their behavior with unconvincing stories, providers often sensed the untruth which risked reinforcing their beliefs about Addicts. It created a double bind: of lying and being viewed as an Addict or of telling the truth and not being believed or feeling judged. If both had the potential to harm the relationship, the value of truth-telling was less clear.

Residents wanted to be treated 'like normal people' and valued opportunities for work, but stories circulated of those who used their roles as volunteers or as employees with projects to obtain extra money or resources. Some residents occasionally invoked the Addict to excuse or deflect scrutiny of their behavior. After telling me how he had stolen drugs from his dealer, a resident shrugged and said, 'what can you expect from an Addict?' (Field Note, 17 February, 2010). While a number of social forces – such as the criminalization of drugs, poverty, stigma, mistrust of and reliance on authorities – made a range of strategies necessary for survival it was difficult to ignore that, while residents resented being treated 'like Addicts', their behaviors often reinforced stereotypes and, in this way, contributed to their oppression.

Attributing their behavior to being an Addict rather than to the many legitimate stressors in their lives was expedient. It would take time to explain how the realities of their lives influenced their behavior without any guarantee that providers would understand. The Addict, in contrast, signified the differences between worlds in a way providers could readily accept as legitimate. Other times, residents' references to being addicts drew attention to the perceived irrationalities of health care. Numerous residents, for example, questioned physicians' reluctance to give drugs prone to misuse on the basis that they already *were* addicts.

### **5.2.2. Different understandings of addiction**

As discussed in Chapter 4, constructions of the Addict in health research reproduce colonial tropes by accentuating pathology, disorder and vulnerability. Yet, residents defined themselves by their strength and resourcefulness. As one explained, 'the strongest, toughest people I met are down here. Like mentally, emotionally tough you know. Wow! To live under the constant stress and threat and all kinds of stuff' (Interview, 1 September 2009). Residents might vocalize self-recrimination for their illicit drug-use, express disdain for Addicts, and resent being treated like Addicts, yet, like the following resident, also took pride in their ability to survive social and economic extremities:

These hard-core drug addicts get up every fuckin' morning and don't know where their money is coming from but by the time they go to bed they've made \$100. They managed to make it magically appear out of the sky. Who the hell can do that? . . . [Y]ou can't do that.

You've been programmed to show up at certain times and collect the pay at the certain time of the week (Interview, 17 October 2009).

Attributes of Addicts were inconsistent with how residents defined themselves as whole people: intelligent, jokers, helpers, sports enthusiasts, loyal parents, good cooks, artists and so on. Stereotypes of the Addict emphasized self-centredness, which failed to consider how residents cared for others including providers and researchers, like the diabetic resident who gave a physician a chocolate bar at Christmas; the residents who presented artwork or cards to providers in appreciation for the help they'd received; or the resident who gave me a gift of new pajamas and a teddy bear (purchased with her monthly welfare cheque) on learning I would be laid up for a month after a surgery.

In contrast to medical understandings of addiction, for many residents drug use was not a problem but a lifestyle and a source of pleasure. 'I do have addictions' one resident told me, 'but it's not a major part of my life' (Interview, 30 April 2011). Another explained, 'My addiction is no longer an addiction, mine's a way of life' (Interview, 30 April 2010). An Addict for a different resident was:

someone that's using bad, hard, everyday – 24/7. Just doing everything that they can to get high is an addict to me. That's pretty well what I do when I go on a binge or something right. Some [people] that just use on the weekends or something, I don't really consider them an addict (Interview, 1 April 2011).

Drug-use sustained many residents through times where the uncertainty and fragility of life was accentuated. Rather than 'falling' into addiction (as some providers and residents described it), addiction kept residents afloat where the full-feeling alternative might have mortal consequences. Without drugs, one Indigenous resident told me, 'a lot of 'em would be killing themselves, I know that' (Interview, 13 April 2010).<sup>40</sup> In this regard addiction was not an obstacle to health but a self-directed therapeutic intervention. As the resident just quoted explained, 'It blocks the pain so they can keep functioning. It keeps them going so that they won't think about "fuck this man – enough is enough!"' (Interview, 13 April 2010). In lives defined by extremity, drugs and alcohol offered one of life's few consolations. 'It's bad enough I have this disease', another Indigenous resident

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<sup>40</sup> Several residents answered questions in the third-person: this enabled residents to express feelings and experiences while shielding themselves from the risk of judgement by depersonalizing statements.

said, 'at least leave me one little thing I enjoy, and that's drinking!' (Interview, 8 March, 2011).

The differences between many providers' and residents' understandings of addiction often refracted different understandings of why residents often delayed access to care. Providers usually explained this in terms of residents' mistrust, not valuing their health, their heavy use of street-drugs and/or poor memories. For providers, the problem of delayed access was located in residents' lives and bodies. These were factors in many instances, but I found other factors were also prominent among residents, such as the belief that seeking care would invite further governance of their lives, the desire to avoid providers' judgement, the value of self-reliance in street life, and – importantly – their resistance to having their lives and bodies exploited. One resident, who stopped attending the Drop-in Centre when staff had not responded to his request for help, talked about removing his name from the list of 'members' so that his life and body would not be included with the statistics to support program funding.

Fear, as noted in other studies of Indigenous and marginalized people, was also a significant deterrent to accessing care (Browne & Fiske, 2001; Browne et al, 2011). One resident explained that he had a 'fear of being judged – judged as an Addict, being positive, living the crazy lifestyle that I was living' (Interview, 21 April 2011). Other residents reiterated his sentiments. Fear influenced how much information residents disclosed. 'A lot of people don't want to say anything [to providers] – they're scared they're not going to be believed' (Interview, 29 May 2010). Another talked about the fear of medical test results and when residents already had more than their share of stress, why would they do something that might add to this? For many residents the risks and dangers of accessing health care often outweighed the benefits.

Residents' desire to be recognized as persons resulted in instances where some deployed the Addict to differentiate themselves from other residents. I noticed this in two instances. The first was among several residents who made a point early in our interactions (and often reminded me numerous times thereafter) of telling me how they were 'not like' other residents who were 'just Addicts'. With the exception of one Indigenous male resident and one Indigenous female resident, all residents who deployed the Addict to distance themselves from counterparts were male settlers. These residents saw themselves differing from counterparts on the basis of being raised in

families with material security; having held jobs (and in one case, having completed a degree); having accrued wealth (signified by owning homes or cars); having been married and had families of their own; and having particular skills, other accomplishments and qualities. A level of socio-economic stability and success in the past suggested it was possible to achieve again in the future, which framed residents' lives in the DTES as a temporary passage. In terms of epidemiological research in the DTES, discussed in the last chapter, settler male residents *were* different from Indigenous, women and young residents: they were (relatively) more educated, with lower infection rates of HIV and higher enrollment in HIV treatment (Craib et al, 2003; Spittal et al, 2002; Strathdee et al, 1997). Settler males were also more successful obtaining regular volunteer roles in the Drop-in Centre during fieldwork and being considered for positions as 'health coaches' with the agency study I evaluated.

The other instance where residents (Indigenous and settlers alike) asserted their difference (and superiority) over counterparts was in positioning themselves to access limited resources and defending the legitimacy of their volunteer roles in the Drop-in Centre. When male residents told me 'you can't trust anyone in the DTES, the unspoken inference was 'except me'. And when a few residents said that almost all of what other residents had told me were 'lies', 'bullshit' or efforts to manipulate me, I sensed they were trying to coax an interview invitation from me by the unspoken inference that they told the truth without self-interest or embellishments to impress me. This mediated asymmetries in power by appealing to my need for information on the basis of their insight and expertise on the world of the street. Much later it also occurred to me that such statements might have reflected the veracity of information they had previously shared with me.

Just as critiques about being treated like an Addict were a way of claiming personhood and worthiness, asserting their difference from Addicts by distancing themselves from counterparts was not only motivated by the aim of cultivating a relationship with researchers or providers but by asserting a claim to normalcy. Indeed, assertions of difference often pivoted on attributes ascribed to 'normal' people: being reliable, a hard worker, a person who cared, and someone with goals. Ironically, residents' declarations of how they were *different* from other residents were also testaments to the way that colonial hierarchies of race, class and gender circulate across society, including the DTES. In contrast to the predominantly settler males who

differentiated themselves in these ways, I found that Indigenous residents often withheld information about their accomplishments. With one Indigenous resident, it was only after several years that I learned she had completed her Grade 12 diploma *twice*, 'for something to do', and only after she passed away, that I learned she had also completed a diploma as a pharmacy technician, which helped explain her frustration when mix-ups in the dispensing of her drugs occurred.

### **5.3. Exploitation: 'They're just in it for the money'**

*We're nothing down here; you know [we're] 'low' people to the [providers]. . . . If it wasn't for me and the other sick people, they wouldn't have a job. (Resident, Interview, 18 September 2009)*

*You know what bothers me? That every person down here on the Eastside who has a chronic disease is worth \$250,000 to any agency around here. That's what the government puts aside. (Resident, Interview, 17 April 2011)*

When I first started hearing residents say providers were 'just in it for the money', I was taken aback. As a health provider, I wondered: how could anyone think this of us? By the end of fieldwork my only surprise was that the statement could surprise providers. While the critique was widely shared, I found Indigenous residents expressed it most often and with the most emotional force; something Flicker et al (2007) also report. As mentioned, Indigenous residents' critiques reflected a greater emphasis on the role of colonial dynamics and inequities in constructing the difference between providers' and residents' worlds; settler residents, on the other hand, were quick to note the ways services profited from their suffering, but more often attributed their circumstances to personal factors and poor choices.

When residents stated that providers were just in it for the money it was often in the context of concerns that they were getting second-rate treatment. For example, on learning a settler resident was given a brand-name drug, an Indigenous resident complained that his doctor only gave him the 'no-name brand'. The belief residents were receiving substandard care was reinforced by the experimental nature of medical practice where physicians often had to tinker with medications and by the research industry's interpellation of residents as study subjects. Suspicions of substandard care and experimentation were expressed in some residents' fears that they were being used

as guinea pigs. I observed such fears more often among Indigenous residents, like the following who told me:

I see people at the HIV place taking a cocktail, I don't know, like four or five pills at once. Why am I taking one pill and these guys are taking five pills? Don't tell me one pill goes where it's supposed to. I think it's just like guinea pigs and they're experimenting with all of this (Interview, 7 July 2010).

When a physician sought to reduce the number of HIV medications to a single pill for another Indigenous resident, he refused, believing that the new treatment would be ineffective.

Criticisms of providers' financial motivations spoke to the moral ambiguity of care where the enactment of providers' duties did not always convey regard for residents as persons. One Indigenous resident told me she once stopped taking ARVs to test whether providers at the pharmacy were motivated by 'the heart' or 'the money'. 'They make a lot of money out of us Native People', she explained, 'they get it out of our Indian Affairs, our band; they get lots of money and then if we stop the pills, they give up on us. That's not right!' (Interview, 20 December 2010). Struggling to contain emotion, she told me how providers in the pharmacy had given up on her after she stopped taking her ARVs. Their indifference to her as a person wasn't only a reminder of inequities, but of the routinized moral violence that was part of bureaucratic care and the systemic discrimination of Indigenous Peoples. The critique providers were 'just in it for the money' was supported by Indigenous residents' observations of the high value settlers attached to money and the economic asymmetry between Indigenous Peoples and settlers' lives generally and between providers' and residents' lives in particular.

Dissatisfaction with health care was widespread, but for Indigenous residents, dissatisfaction was intensified, being seen as evidence of ongoing systemic discrimination of Indigenous Peoples and economic injustice. The affective currents between dissatisfaction, discrimination and injustice could be unleashed by numerous practices, but often revolved around medication, such as beliefs that physicians were trying to save money by prescribing less expensive (and less effective) generic medications, by their reluctance to prescribe certain medications, or conversely, by making money for themselves or others through the prescription of drugs. Most medications that physicians prescribed were dispensed free of charge – the federal

government covered the cost of medications for Indigenous residents with Indian status, and the costs for the remaining residents were assumed by the BC Ministry of Health. However, because pain relievers (such as Tylenol 3 or morphine) were usually prescribed in small numbers and for a specific period of time, if residents used up their pain medication and needed more before the physician would issue another prescription, the only option was to purchase the medication on the street. Why, Indigenous residents complained, should they be forced to buy medications on the street when the government covered the costs of their health care? Whether it was a Tylenol 3 (T3) for 50 cents or a morphine pill for \$20, Indigenous residents argued that they shouldn't have to spend their limited income on medicine. The injustice of having to pay for pain relief reinforced the sense of injustice that came with feeling providers didn't take their complaints of pain seriously. Since it was primarily Indigenous residents who made such remarks, I also interpreted them as responses to ongoing economic injustice that had its foundations in colonial dispossession and systemic discrimination.

Encounters with several Indigenous residents illuminated the connection between bodies, money and care. One resident avoided taking ARVs for two years because he believed the provider was 'just after my money'. When he told me this, I was bewildered and thought, 'what money? You don't really have any'. At the time, I interpreted being 'after their money' as the fact that providers billed the government for services rendered. This was only part of the explanation. He later added that a health provider might promote treatment in an effort to extract bodily resources, such as blood or teeth, that could be later sold for financial gain. Initially, I wondered how he could complain since he was getting the life-saving, costly ARVs for free, a logic that followed the moral-economic logic of providers which valued ARVs for their contribution to physical well-being and saw ARVs, like other social benefits, paid for by taxes. This logic was premised on liberal beliefs that didn't consider the socio-historic context of meanings and expected the poor to be grateful for aid.

A second resident, Nick, complained in almost every interview with me that his physician '[will] give me \$10,000 of ARVs but won't even give me 14 T3s every two weeks – he thinks I'm going to sell them'. I was even more confused when, at the end of fieldwork, Nick disclosed 'sometimes I do sell a few' indicating that any fears the physician had about his diverting drugs were well placed (Field Notes, 3 March, 2011). I came to see that Nick's complaint was not about the either/or truth of his pain or whether

he did/didn't divert drugs. The short answer to each was 'both', but the long answer lay in inequities and a desire for economic justice. Having seen foster parents, welfare workers, and providers make a living from his care while the conditions of his life remained bleak, Nick wanted a chance to benefit from his bioresources as well. These two residents recognized their diseased bodies as economic resources (Elliott, 2007), but it was virtually impossible to harvest their bioresources except through professionals. Nick was frustrated seeing the wealth represented by his bioresources dangled just beyond his reach, telling me:

A couple of people are telling me, 'oh, you're a goldmine, you can get . . . a bunch of pills (when you're HIV+). Some pills sell for five bucks each and stuff like this. . . . You can get Viagra if you've got HIV. . . . You're a goldmine, you're a goldmine!' A couple of people have told me that, eh, and I can't even get T3s. They said, 'there is something wrong there'. They said 'I know people with HIV and they're a goldmine, they're getting pills galore' (Interview, 4 June, 2010).

For Nick, the belief that providers were 'just in it for the money' was a self-fulfilling prophecy. Over multiple interviews he reported feelings of abandonment and not feeling cared for by providers, which he attributed to providers' preoccupation with the 'almighty dollar'. Nick wanted to be cared for as an individual and resented being objectified. Yet, in our interactions he made no attempt to temper his economic objectives and often greeted me with blunt requests for a toonie or an interview which left me feeling objectified as a cash-cow and caused me at times to avoid him. The objectification he had experienced throughout his life in relationships with authorities was reproduced in the way he viewed his body and how he continued to interact with myself and providers.

The belief that providers were 'just in it for the money' and profited from residents' bioresources can be seen as part of a longer history: Indigenous Peoples' lands and bodies *were* paying for services – as money generated by the government from the dispossession of lands flowed through the management of residents' bioresources to providers. Indeed, one resident acknowledged that his HIV infection 'paid the rent' by the fact he had received a housing subsidy through the Drop-in Centre. But overall, in the present day, the vast number of helpers that zig-zagged across the bioterritory of residents' lives and bodies, accumulating economic capital in the process, came and left while the suffering and conditions of the residents' lives changed little. This sowed suspicion, cynicism, and resentment toward those who derived economic

benefits in the name of care. There were more services and better housing, but most residents were still poor, still judged, still treated as children, while helpers could afford cars, homes and holidays. Some providers agreed: 'Their lives were crap before, they are still crap' (Interview, 7 May, 2010).

## 5.4. Health work

Mindful of their reliance on providers, many residents worked hard to build and maintain supportive health care relationships. Residents' health work often focussed on encouraging the provider to see the resident as a person and as a worthy subject of care. If providers were pleased, residents found they were more likely to get their needs met. With a few residents, however, health work involved limiting their contact to reduce the likelihood of the provider saying or doing something that would anger the resident. For these residents, health work maintained the providers' physical safety and preserved the residents' access to health care. Regardless of the approach, residents' health work tended to be successful to the extent it remained unnoticed by the provider. If noticed, it risked being interpreted as the manipulative behaviors of Addicts.

One form of health work was 'being professional'. As one resident explained, 'you get way more help from trying to be a professional guy . . . [or] a professional client' (Interview, 1 April 2011). This meant being patient, pleasant, and co-operative. Health work often involved satisfying providers' need to feel helpful by conveying an interest in one's medical care and being receptive to their advice. In my interview with one resident, I recorded the following field note where he told me:

I pretend I hear and I appreciate their care; I let them think I'm hearing but I'm tuning them out'. It enabled him to manage their involvement and influence in his life. 'A general rule down here is don't volunteer information – the less they know, the less they'll pry'. He tells them just enough to satisfy them [and] get them off [his] back (2 September 2009).

Astute observers of social life, several male residents told me they wore the 'phoney smile' when interacting with providers. To increase his consideration for housing subsidy, one resident reported visiting the Drop-in Centre almost every day for many months: 'When I didn't want to smile, I smiled. I just kept being nice, . . . [irrespective of the fact I was] totally stressed out' (Interview, 28 July 2010). He had been cautioned by counterparts that providers would 'test' him to see how he reacted under stress to gauge

his suitability as a tenant. 'I don't know if that's true', he said 'but [providers] told me a couple times that [a housing subsidy] coming up . . . and it never happened. I think they told me to see how I'd react' (Interview, 28 July 2010). Health work didn't end with getting the desired resource. One resident who had received a housing subsidy made regular, calculated 'appearances' to let providers' know he was doing well and deflect the chance of unannounced home visits. In the Drop-in Centre, I also observed that residents who held volunteer positions often acted as ambassadors of the program when interacting with visitors and media, by only talking about the positive aspects of the program. One resident-volunteer explained it as 'being faithful, like you're faithful to your woman' (Interview, 22 June, 2010).

Health work was often a testament to residents' ingenuity and amiable nature. One Indigenous resident described how she appealed to providers at 'their level' by inquiring about her medical information, such as the results of her blood work, and then gradually brought them 'down' to her level through the use of humour. In the process she usually found that providers' demeanour softened and they became more receptive to her concerns. To see such behaviors as manipulative would overlook how the colonial dynamics of power in health encounters made health work necessary. It would also overlook residents' acumen in realizing that both parties brought their interests to encounters and that relationships (and care) flowed better when providers' priorities were acknowledged.

Survival enabled many residents to become adept observers of individuals' 'soft-spots' and needs. Providers' eagerness to help sometimes resulted in behaviors that several residents described as 'over-care'. Over-care referred to instances when providers went beyond the usual parameters of health care interactions, such as bringing gifts or special food for residents. Responses to over-care varied: some residents welcomed the attention, while others were suspicious and/or wondered what they might be asked to do in return. What is relevant here is how the recognition of providers' need to help and desire to cultivate a connection, informed residents health work. And, when over-care aroused suspicion, it became one more aspect of the encounter that residents' health work sought to manage without eliciting discipline or alienating the provider.

Health work also involved refraining from critique and suppressing signs of displeasure and frustration. Realizing they were unlikely to come out ahead if there was a difference of views, some residents responded by avoiding certain providers and withdrawing for periods of time. One resident explained:

Having to deal with these type of people all my life and knowing what's best for me. I have to work within certain guidelines or it's just not going to work [or] I'll be in jail. . . . I have to try really hard. I have to play by their rules. There are no other rules (Interview, 23 December 2009).

Some residents were unwilling, unable or refused to adopt a submissive posture, and tried appealing to providers on the basis of their intellect. This strategy was less reliable, often eliciting a defensive responses and discipline. I observed that some of the most marginalized residents (in terms of services) were those who were most *like* providers in terms of their assertiveness and insistence on being treated with respect.

Health work was also evident after minor conflicts or misunderstandings. Following an incident (real or imagined), residents often returned to apologize irrespective of whether they saw themselves at fault or not. A few residents explained it as the need to 'keep the relationship going'. As mentioned, positive relationships with staff were important for several reasons. In addition to protecting access to services, the affirmation, trust and stability of some relationships offered a refuge from street life. Another factor in some residents' health work was fear about the contagion of negativity – that if a provider became angry they would turn other providers against them. In this regard, health work concurrently sought to manage relationships with numerous providers. Given the importance of avoiding displays of vulnerability in street life, I saw residents' apologies as significant concessions to power, demonstrating the importance of health services in residents' lives and the value many attached to positive relationships. Providers rarely apologized for misunderstandings or mistakes but when they did it was significant. One provider I interviewed shared two incidents where she'd overstepped her boundaries and later apologized to the resident. Both incidents later surfaced spontaneously in separate interviews with each resident. Apologies confirmed what residents well knew: providers were imperfect and sometimes misused their power. By recognizing limits in her practice, the provider communicated her humanity and respect for residents. Both apologies marked a turning point in residents' relationships with the provider.

In drawing attention to the work residents' do to access care and build relationships with providers, it's important to note that similar strategies are also used by providers to cultivate relationships with residents. While providers' tactics are often recognized by residents, they usually 'played along' in an effort to get their own needs met. For both parties, relational work is oriented to achieving particular aims. What is significant here is that providers' strategies and aims are legitimized as necessary and worthy, while the strategies and aims of residents – if perceived by providers – tend to be discounted and attributed to the manipulative or 'drug-seeking' behaviors of Addicts.<sup>41</sup>

## 5.5. Conclusion

Residents expressed three main critiques of health services: 'they try to control you', 'they treat you like an Addict', and 'they're just in it for the money'. This study shows that residents' lives are governed by multiple regulatory processes and institutions. I contend that recognizing the broader regulatory context of residents' lives is essential for understanding residents' experiences of and responses to the regulatory regime of health services. The proliferation of rules also makes residents acutely aware of their precarious status and reliance on health providers for assistance with a range of concerns and compounds the difficulty they face in expressing their needs and critiques.

The figure of the Addict plays a large role in health care interactions. Residents experienced being treated like an Addict as infantilization, objectification and being treated like a number. Above all, it was felt as an injustice in its affront to residents' personhood. Being treated like an Addict is very different from the experience of *being* an addict. Where providers' understandings of addiction emphasized pathology, disorder and need, for residents' drug use could also have many other meanings such as a source of pleasure, community, a lifestyle, and a means to cope with painful memories: illicit drug use, for many, was not seen as problematic.

Finally, residents' critique that providers were 'just in it for the money' illustrates how the disjuncture between costly treatments and the enduring inequities of residents' lives reinforced beliefs about providers' pecuniary motivations. Indigenous residents

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<sup>41</sup> 'Drug-seeking' refers to a number of behaviors that residents' seen to use when seeking prescription medication for non-therapeutic purposes.

more often voiced this critique, and I found that inequities between the resource-intensive investments in providing care and the poverty of residents' lives led many residents to view their bodies as an economic resource.

## Chapter 6. Boundaries, relationships and time

*Building relationships, navigating complex health issues and setting appropriate limits are tough to balance. (Physician, Email Correspondence, 3 May 2013)*

In the last chapter, I discussed how many residents negotiated the asymmetries of power in health care relationships through their health work. Although health work could be directed to achieving several aims, it often sought to build and maintain a supportive relationship with the provider to reduce the social and affective distance in their relationships. I argue that one factor that contributes to sustaining beliefs about Addicts and makes this health work necessary, is the prominent emphasis providers in the DTES place on 'professional boundaries'. A critical examination of professional boundaries is the focus of this chapter.

Although I have worked in many communities and health settings as a nurse, I have never been in an area where professional boundaries were so prominent in everyday interactions among providers. I argue that the heightened emphasis on professional boundaries in this setting was a response to the equally important emphasis placed on developing relationships with residents as a condition for the delivery of care. The dual emphasis on boundaries *and* relationships in the DTES created a constant tension for providers in health care relationships in the need for distance *and* proximity.

Professional boundaries are helpful and necessary, but in this chapter, I contend that professional boundaries can also enact harm by structuring relationships in ways that reproduce colonial hierarchies of power in relationships with Indigenous Peoples. For example, the discourse of professional boundaries gives little attention to *patients'* boundaries. In this study, providers often transgressed residents' boundaries (or biosovereignty) but such violations were largely unrecognized by providers. The selective in/attention to who has (and doesn't have) boundaries reiterates the colonial principle of 'terra nullius' (nobody's land) which rendered the violence of colonial occupation and governance invisible to officials. In health care, providers alone determine whether the boundaries of relationships were therapeutic (beneficial) for patients, mirroring the moral determinations of colonial officials in presuming to know what Indigenous Peoples did and didn't need. In other words, the sequence of

benevolent concern, therapeutic aims, intrusive practices, and subsequent harms, which usually passed unnoticed in providers' discussion of professional boundaries, re-enacted colonial relationships with Indigenous Peoples.

In this chapter, I argue providers' notions of professional boundaries, why they are important, what they consist of and how they are drawn, is selective. And that boundary discourse was not only problematic for residents but could also subject providers to the colonial violence that pervades health care structures. Participants' understandings of boundaries and their responses to these varied. For example, several providers resisted conventional understandings of professional boundaries and were attentive and responsive to residents' experiences of their care. And while many residents preferred more relational forms of care, there were also residents who preferred providers with conventional boundary practices which maintained social distance. Although colonial dynamics privilege providers' boundaries, many positive health care relationships still formed. I argue that these relationships, which I conceptualize as health care alliances, temporarily ameliorate the colonial dynamics of care by drawing upon the generative power of personhood. A broader conceptualization of professional boundaries would include greater diversity in understandings and consider patients' boundaries. I contend that also considering the temporal and moral dimensions of boundaries would bring care into better alignment with residents' perspectives, priorities and readiness to change and, in this way, communicate greater respect for their personhood and right to self-determine.

## **6.1. Professional boundaries**

In Chapter 3, I explained the ethical dilemmas that arose as I negotiated my research relationships with residents as an anthropologist with my obligation to maintain professional boundaries as a nurse. Several problematic assumptions and aspects of professional boundaries became evident during fieldwork, including the way providers' understandings of professional boundaries could function as a way of morally policing each other's conduct. All professionals that are regulated by the Health Professions Act, such as physicians and nurses, are expected to ensure public safety by reporting providers with unethical and unsafe practice to their respective professional college. The more obvious violations include sexually or economically exploiting patients and causing

harm through negligence. The moral policing I am referring to, however, was more subjective and applied to providers whose practice in every other respect would be deemed competent. Providers who described being the subjects of their colleagues' moral censure attributed it to colleagues' emotional exhaustion (or burnout), colleagues' not wanting to have the expectations for their own performance increased, or employers' efforts to standardize services through greater governance of staff. Reflecting on my own struggle with the emotions evoked by witnessing residents' suffering, discussed in Chapter 3, it is also possible that the moral violence enacted laterally among providers, reflects the need to exercise some agency in our everyday lives and practice, when the macro-level forces that create this suffering are beyond our influence.

### **6.1.1. Why professional boundaries matter**

Professional boundaries are elaborated in professional codes of ethics and are central to notions of professional conduct and competence. The importance of professional boundaries reflects awareness of the inherent asymmetries of power in health care relationships. Professional boundaries aim to prevent providers from misusing their power and harming patients. To keep patients' concerns at the centre of care, the normative discourses of professional boundaries discourage providers from sharing personal information or opinions. The College of Registered Nurses of British Columbia (CRNBC) Practice Standards for Boundaries in the Nurse-Client Relationship (2018) elaborate provider-patient boundaries in great detail. For this reason, I use CRNBC as my referent for the analysis in this chapter. CRNBC defines the professional relationship as:

therapeutic and focuses on the needs of the client. It is based on trust, respect and professional intimacy, and it requires the appropriate use of authority. The nurse-client relationship is conducted *within boundaries* that separate professional and therapeutic behaviour from non-professional and non-therapeutic behaviour. A client's dignity, autonomy and privacy are kept safe within the nurse-client relationship (emphasis added).

Violations of professional boundaries have typically been associated with providers being too involved rather than being too distant from patients (College of Physicians and Surgeons of British Columbia [CPSBC], 2018; CRNBC, 2018). Residents' critiques attest the problem of providers who become too involved, but residents also reported harms

from providers being too distant – something that is now recognized by CRNBC. I found that excessive distance could harm residents by practices or a felt presence that was experienced as indifference to their concerns, personhood and social realities. I observed this when providers did not engage or seriously consider residents' concerns, when providers' recommended interventions that were inappropriate to residents' realities and evaluated residents' behavior within the norms, moral assumptions and economic realities of providers' lives.

Providers in this study identified several ways that professional boundaries facilitated care. Physicians said that boundaries created the distance needed to maintain good clinical judgement. Becoming emotionally involved with the patient could cloud medical judgement and make the provider reluctant to initiate painful investigations or treatments. 'That's why', one physician explained, 'we don't treat our families' (Interview, 19 April, 2010). Social distance also contributed to the 'mystique of the physician' (Interview, 7 May 2010) which some physicians said helped reassure patients and alleviate their worries. I found that a level of professional distance could benefit care in another way. Many residents censored the information they shared with authorities to avoid jeopardizing the providers' regard or eliciting judgement. In a close relationship, resident might be tempted to disclose information about their lives in a moment of intimacy that may have altered the providers' ability to relate to the resident and/or, left the resident feeling emotionally exposed and unsafe. When providers maintained a level of professional distance it reduced the chance of such disclosures.

I contend that the emphasis on boundaries in the DTES was also a response to the equally important emphasis providers placed on relationships and the potential dangers that relationships with residents were seen to present. It was important to get close (at least closer than was common in other health settings) but not too close. And it was important to care but not too much. Professional codes of conduct assume that providers have the knowledge and ability to enact boundaries prior to interacting with patients. For most providers I met, the DTES was their first experience delivering care to an impoverished clientele who faced multiple social and health challenges. How does one learn to set boundaries with people living in an area of social extremity without prior experience of these settings? What happens when boundary precepts, formed in settings where most patients have stable housing and trust authorities, are carried into areas where the social terrain is uncertain and many patients mistrust authorities?

### **6.1.2. Working out boundaries: A provider's responsibility**

As discussed in Chapter 3, my effort to understand the history of HIV services in the DTES brought me into contact with many providers employed by other agencies within and outside the neighborhood. I mention this because my examination of professional boundaries was not limited to my observations of and interactions with providers at Native Health. Despite having standards of practice and resources to guide practice (CRNBC, 2018), each provider I met had to work out the meaning of professional boundaries in the DTES for themselves. This involved observing and speaking with colleagues and experimenting in practice. Like ethnographic fieldwork, building health care relationships in a setting of social extremity is an improvisational practice where ruptures, misunderstandings and mistakes are inevitable (Cerwonka & Malkki, 2007). In health care, however, improvisation occurs in a professional context that expects competence and is often unforgiving of shortcomings. Very few providers talked about their difficulties, mistakes, or the unconventional practices they sometimes used to facilitate residents' engagement in care. As a result, the learnings derived from such practices (Simpson, 2017), remained invisible and unable to strengthen processes of care.

Discourses of professional boundaries are predicated on a moral binary that allows providers only two options: practicing therapeutic/good/healthy boundaries or un-therapeutic/bad/unhealthy boundaries, which correspond to being a 'competent' or 'incompetent' provider. Openly acknowledging one's difficulties, confusion, and shortcomings with professional boundaries risked raising questions about the one's professional competence. Over the course of fieldwork, I realized that the moral binary of good/bad boundaries and the risks associated with being perceived as too involved created a third option of covert practice, concealment and disavowal. After observing the unconventional practices of one provider, she asked me to remove any reference to them from my field notes and did not wish to discuss the matter further. The lingering impressions of the shame, fear and silence I sensed with this provider and several others with unconventional practices were also consequences of the violence inherent in professional boundaries. This resonated with the triad of shame, fear and silence so often identified by Indigenous scholars as affective responses to colonialism (discussed in Chapter 2). Such silences sustained conventional understandings of professional boundaries and allowed colonial hierarchies of power in health care to remain seen as

legitimate and necessary. As I learned about the importance of personhood for many residents, it also became more apparent how professional boundaries, which were predicated upon and protected Western notions of individual autonomy, could create a barrier to the kind of care – *relational care* - that facilitated many residents' access and experience of well-being.

Boundaries helped set limits around what providers did/didn't do and reduced the likelihood of being drawn into residents' lives beyond providers' emotional threshold. The difficulty – especially in for those roles outside of structured clinical settings – was where to draw the line.

Professional boundaries are predicated on beliefs that providers have 'influence, access to information, and specialized knowledge and skills' and that patients have needs (CRNBC, 2018). But, as I show in subsequent chapters, providers' knowledge and skills were often inadequate to understand or address the challenges of residents' lives, and to recognize and incorporate the vitality that was as much a part of their lives as suffering. Even when providers' knowledge may have been able to address residents' physical concerns, their limited understanding of residents' perspectives, strengths, and social context could be an obstacle to care. Providers' inability to recognize the limitations of their knowledge and moral aims was a recurrent frustration for many residents in this study. Residents had specialized knowledge and skills forged through their poverty, marginalization and ability to survive on the street, but the hierarchy of knowledge, norms and moralities of health care allowed little room to consider these, thus reinforcing providers' beliefs about residents' vulnerability. To be clear, it was not always that residents wanted to share their knowledge as much as they wanted providers to recognize that their knowledge, experience and moral claims were limited and contingent.

CRNBC (2018) asserts that the responsibility for setting and maintaining boundaries 'always' resides with the nurse. While there were reasons for this, the idea that providers were solely responsible for setting and maintaining boundaries reinforced the hierarchy of encounters and positioned relationships as sites for professional management. I found that providers explicitly communicated professional boundaries when they perceived residents as demanding or rude, when pressed for time, and when required to field requests, like being asked for a toonie or for pain medication. As

discussed shortly, the one-sidedness of providers' understandings of boundaries rendered residents' perspectives, experiences and agency invisible. It created the conditions for providers to transgress residents' boundaries without any awareness of how they may have violated and harmed residents. It also made them oblivious to the ways that residents *also* managed relationships through their health work.

Professional boundaries also pertain to relationships *between* providers, especially in the duty to safeguard patients' health information.<sup>42</sup> While providers are required to respect patients' privacy and confidentiality, they are also legally authorized to share patients' health information on a need-to-know basis as it pertains to patients' ongoing care. There is no acknowledgement that patients' understandings of confidentiality may differ. Many residents were unable to reconcile the fact that providers often told them ('promised them') that the content of their interactions was confidential with the later realization that their personal information had been shared with other providers. For these residents, confidentiality meant not sharing information without their explicit, prior consent. CRNBC (2018) stipulates that nurses will inform patients that health information will be shared, with whom and why, but this was difficult to implement since many residents didn't have telephones, their attendance was often sporadic, and the flux in providers schedules, duties and time-pressures worked against this.

The challenges were greatest in the Drop-in Centre given the broader scope of its services, the number and range of providers constituting the team, and the requirement for continuity in a service open seven-days per week. The more personal and social nature of many relationships also presented a challenge. As the needs of particular residents were discussed during the Drop-in Centre staff meetings, various staff added context and insights from their interactions with residents. It was often difficult to differentiate information that was shared on the basis of it being necessary for health care from information shared on the basis of providers' knowledge of and/or affection and care for the resident as a person. The discussion of residents' personal and health information also functioned as social glue to affirm unity of 'the team'. For a few providers, sharing details about residents' lives also functioned as a form of professional capital by drawing colleague's attention to the providers' skill in developing relationships. Although residents' often critiqued providers for breaching confidentiality,

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<sup>42</sup> CRNBC (2018) addresses this in the Practice Standard for privacy and confidentiality.

they couldn't see the covert practices some providers used to protect residents' health information. For example, documentation is a standard of professional practice, but in many cases how something gets documented is a matter of professional judgement. When a physician asked a nurse in the Drop-in Centre to provide follow-up care for one residents' sexually transmitted infection, in order to protect the residents' health information, the nurse documented it in the Drop-in Centre's records as 'care provided per [the physicians'] orders' without any reference to the infection (Interview, 11 March, 2010). When reviewing medical records of a few residents (with consent), I noticed that sensitive information discussed with their physician in some encounters was not documented but held in the vault of their physician's memory.

### **6.1.3. Vulnerability: Patients, providers and personhood**

Professional boundaries are informed by assumptions about patients' vulnerability. As explained in Chapter 5, residents define themselves by their strengths and resourcefulness. While the asymmetry in power and burden of inequities did place residents at significant disadvantage, I found when providers talked about the importance of professional boundaries in *practice* it was usually a response to their own feelings of vulnerability and the perceived risks of interacting with residents. The importance of boundaries in this regard, emphasized self-protection with respect to the risk of manipulation and to the needs for emotional self-preservation and personal safety. Some providers' concerns that more personal forms of engagement made them vulnerable to manipulation were not unfounded as residents' health work could involve leveraging relationships to gain access to resources. While this was more of a concern for providers in areas like pain management, as discussed in the last chapter, residents sometimes resorted to covert tactics because efforts to express their concerns directly were unsuccessful or elicited sanction. Relationships with residents also carried emotional risks. Empathy, some providers said required opening oneself to others and being able to 'feel their pain'. While embodiment was an aid for assessment, diagnosis and intervention, the challenge was not letting pain 'get stuck' in one's body – something one physician described as 'vicarious trauma' (Field Notes, 3 June, 2010; Scholten, 2017). Providers' desires to help, combined with the complex challenges of residents' lives, made them vulnerable to giving beyond their resources. Being assigned sole responsibility for the relationship and the delivery of care (as defined by CRNBC), also

made providers vulnerable to taking too much responsibility for residents' health. After many years in the area, one provider had observed how some colleagues 'lost themselves' in residents' lives to the point where their identities, actions and responses were subject to the flux in residents lives and addictions. 'It's like you've taken on their persona,...you're not yourself anymore' (Interview, 1 July, 2010). The conditions that created residents' suffering were beyond the scope of any provider to address. The constant exposure to the difficulties of residents' lives and the recognition of the limited range of interventions that could alleviate non-physical sources of suffering were emotionally draining. The challenges were compounded, physicians said, by very limited local access to psychiatric and mental health resources. Even without the complexity of this setting, the problem of 'professional burnout' is rife among physicians and nurses (Canadian Medical Association Journal, 2017; Canadas-De la Fuente et al, 2015).

In practice, professional boundaries were observed in the guardedness of providers in sharing information about their personal lives with residents. The discomfort with personal questions was most apparent among some physicians who responded by ignoring such questions, offering cryptic responses, turning away, and/or quickly directing conversation back to medical matters. One physician explained that he withheld more personal information from patients in the DTES than he would from patients in a practice outside the area lest a disgruntled resident target his home, personal property or family. I found this caution reasonable, having listened to the violent fantasies of one resident and heard of one instance where a resident threatened 'to get' the provider after work. Yet, I also observed that some physicians' openness to questions about their holidays or families were important for several Indigenous residents' engagement. For example, the only time one Indigenous resident 'woke up' and displayed any interest in his clinical interaction was when he initiated a brief exchange about the physician's recent holiday and family.

The unidirectional assumption of 'professional boundaries' fails to consider that for both parties health care encounters involve vulnerabilities and fears. For relationships to work, both parties are required to take risks. The risks for providers included facing one's limitations, having one's trust betrayed, feeling manipulated, having prescriptions diverted to the street, and having items stolen. These risks could be mitigated to some extent by exercising greater caution or imposing more rigid boundaries or sanctions. While enacting such strategies increased the likelihood of residents feeling treated like

Addicts, what I draw attention to here are the asymmetries in terms of whose risks are recognized and in the respective options available to manage these. Interactions with providers also carried significant risks for residents, which I discuss further in Chapter 8, such as exposure to judgement, governance, breaches of privacy, and feeling their concerns were dismissed. All of these could heighten feelings of demoralization, provoke anger, intensify mistrust and alienate residents from care. To preserve the relationship residents worked to contain their frustration. To express such feelings openly risked the domino effect of sparking providers' fears, eliciting sanctions, reinforcing beliefs about Addicts, eroding the relationship and, for the resident, potentially forfeiting health care.

Professional boundaries assume that knowledge and resources flow in one direction, which is at odds with the intersubjective realities of many interactions and several providers' descriptions of their work. It was not only residents who derived benefits: Several providers told me that working with residents satisfied their needs for meaning, restitution and/or commitment to social justice. A few providers also said that relationships with residents contributed to their personal growth and healing. Forging a better relationship not only facilitated the delivery of care but also humanized care, allowing some physicians' to feel more whole and present in the encounter. One physician who had talked the importance of being able to empathize and 'feel' residents' pain, described the personal costs of maintaining professional distance:

I think you miss out . . . in terms of emotional experience with your patients 'cause I kind of thrive on [the] real connection with people that you get. And if you're always that distant, you don't have any kind of connection with patients. . . . You're lonely . . . it depends on the personality of the doctor – me I need that, or want that, or feel it's important (Interview, 7 May 2010).

The importance of a more personal engagement, for some providers and residents alike, drew my attention to how the discourse of professional boundaries accentuated Western assumptions of persons as bounded and autonomous.

#### **6.1.4. Professional boundaries as moral policing**

Listening to providers' stories of 'bad' boundaries, I realized that their boundary discourse was an informal way of morally policing providers and maintaining the status quo: Providers internalized and enacted the colonial moralities of boundaries among themselves. Policing is embedded in the CRNBC (2018) principle that: 'Nurses help

colleagues to maintain professional boundaries and report evidence of boundary violations to the appropriate person'. I was not interested in infractions, such as sexual relationships or 'partying' with clients, but in those that were more subjective, where there was not a clear consensus. I found few providers criticized colleagues' practices directly but their opinions circulated informally through stories of caution around things like bringing residents food or other items from home, hanging out in the area on days off, giving residents money, meeting residents for coffee or meals, and offering residents temporary shelter in ones' home.

Providers alleged to have 'crossed the line' by becoming too involved paid the price in emotional exhaustion, losing colleagues' respect, professional discipline, and at the extreme, having their jobs and professional licenses placed in jeopardy. There was no question that being perceived as 'too close' or 'too involved' placed providers in peril. When I interacted with several providers employed by the health authority, I noticed that they glanced over their shoulders and lowered their voices when talking about their interactions with residents. A few also described having to censor discussion of their practices with colleagues who had openly questioned their practices in staff meetings and/or reported their 'boundary problems' to supervisors. Although Native Health as an institution was more attuned to providers' personhood and encouraged more personal responses to residents, providers there were also influenced by moral policing. For example, a provider who agreed to give a resident a ride somewhere after work arranged to meet the resident at an intersection outside the DTES to avoid being seen by colleagues. The precaution reflected the provider's awareness that the practice would be frowned upon by colleagues. The fear some providers conveyed when talking about their relational practices was palpable and had nothing to do with residents. Clearly, professional boundaries were not just about maintaining one's relationships with residents but were also about maintaining relationships with one's colleagues and employers: something that involved being perceived as conforming with professional norms.

It was significant that the stories of bad boundaries shared by providers always pertained to the practices of others. These stories asserted certainty in relational terrain that was, by definition, uncertain. Such stories simultaneously attracted and deflected attention from the speaker. It drew attention to the speaker's implicit claim of ethical conduct while directing the listener's thoughts to less-ethical others. Residents' stories

and a few observations of my own suggested that some of the most vocal proponents of professional boundaries had variable practices on the ground. This wasn't surprising because the realities of developing relationships and delivering care were complex. What caught my attention was the shroud of secrecy, the disavowals and the subtexts of shame and fear that attended covert practices. These observations, combined with my own experience working as a nurse, enabled me to see how providers were also subjected to and could be harmed by the colonial dynamics of health care.

By asserting the need for distance, boundary discourse discouraged providers from gaining more complete knowledge of residents' lives and from understanding the limitations of services in situ. Distance helped to maintain colonial hierarchies of power in the delivery of services irrespective of (and oblivious to) how the limitations in providers' knowledge and practices might decrease the relevance of care and/or harm residents. Getting to know residents as individuals placed the border between worlds in jeopardy. As relationships became more personal they risked being less about roles and more about the connection between human beings. It is not that providers lost sight of their professional obligations (although this could and did happen) but that their understanding of these obligations in terms of what did and didn't help and how far they extended themselves to help could change over time. In some cases, it was only when providers became exhausted from their emotional investment that they were able to formulate a deeper, embodied knowledge of professional boundaries for themselves. Some said they learned to be more attentive to their body's responses. For example, one provider found that shoulder and neck pain were important cues to reviewing her boundary practices.

Stories of bad boundaries overlooked this processual nature of providers' and my own understandings. There is some recognition of the processual nature of understanding boundaries in the latest revision of the CRNBC Practice Standard on boundaries, dated 26 April 2017. For example, CRNBC recognizes that some boundaries are not clear cut and encourages nurses to discuss complicated situations with a trusted colleague. But this statement co-exists with the moral policing function which is encoded in the requirement that nurses also 'report evidence of boundary violations to the appropriate person'. The intent to support nurses' exploration and self-learning is nested in the context of censure. It cannot be otherwise as the primary role of CRNBC, like other professional colleges, is regulatory.

While many residents conveyed little interest in interacting with providers outside their hours of work, for some, providers' efforts to reconcile the tension between distance and proximity in health care relationships resulted in mixed messages. One resident accused providers of trying to get all 'chummy chummy' and giving the impression they wanted to be his friend. When the resident reached out to one provider 'off-hours' he was told not to call her at home, leaving the resident feeling angry, humiliated and betrayed. Feeling cared for as a *person* was difficult to reconcile with the idea that care, like a lamp, could be switched on and off, with the provider alone controlling the switch. Providers were often in a double-bind: of recognizing the need to be more personal and flexible in their relationships with residents, which could risk the judgement of colleagues, or of more narrowly interpreting their roles and alienating residents, to be 'professional'. It was a particular challenge for providers in non-clinical and less structured outreach roles where the resident's only interest in or need for the service might be the relationship.

### **6.1.5. 'Co-dependent' health services?**

The notion of professional boundaries posits the professional as an autonomous actor who influences the patients' behavior without becoming 'too' involved. Yet, health care is an interdependent practice with each bringing interests and with impacts for patients and providers alike (Frank, 2004; Hilfilker, 1994). Patients' acceptance of interventions was important for providers' professional sense of accomplishment. In his examination of health care among inner city poor, Brodwin (2011) found that providers' inability to fulfill their therapeutic aims when patients refused care led to feelings of futility and despair. Providers varied in how they responded to residents' suffering: A few reported little difficulty while others reported being deeply impacted.

Many residents recognized the DTES was a difficult place to work and several noted how new providers would arrive open, engaged and eager to help but over time began withdrawing emotionally, became irritable and more rigid. Subsequent chapters document the harms caused by providers being 'too pushy', but what fewer residents acknowledged was that such behaviors might *also* be the provider's way of coping with suffering. The emphasis on ARVs was motivated by providers' desire to prevent unnecessary suffering, but I believe in some cases, the promotion of ARVs was also a *salve* for the suffering of witness. Pressing residents cultivated an illusion of control in a

setting where the resolution to most problems lay *beyond* the purview of providers' influence. Yet, many providers' income, roles, and professional esteem were directly linked to promoting improvements in residents' health. With the limited arsenal of interventions that could alleviate suffering, if residents declined such interventions, the justification for providers' presence in the DTES was open to question. If providers were unable to deliver care, then perhaps their role of 'exercis(ing) power over other human beings [was] for no good reason' (Dyck, 1991, p.77).

The following excerpt from my field notes relates a discussion I had with a nurse, Bonita, in the Drop-in Centre who acknowledged being 'a bit pushy' at times:

If they don't take their meds and they end up sick, they come to [the Drop-in Centre] and ask for help. I asked if seeing them in this state aroused feelings of guilt. 'Yes', because she thinks about her daughter when she thinks about patients. . . . It's difficult to see them really sick knowing it was completely preventable. Hounding people to take their meds is easier to handle emotionally, easier to live with, easier to bear. . . . Intellectually she understands the right to refuse, but is unable to process it emotionally. . . . 'The problem', she said, 'is I'm a control freak. It's something many nurses struggle with. For those that refuse, I try everything I can – I don't want to work in a place that I can't accomplish what I was hired to do'. When residents take their meds, she feels she's doing her job; it validates her as a nurse. 'It helps me to help them'. At this point I paused and noted that most of her reasons reflected her needs. She readily agreed, 'it's all about the provider' (Field Notes, 31 October 2009).

Bonita attributed her behaviors to an 'addiction to care'. The addiction to care, like the addiction to drugs, was ultimately an attempt to quell personal distress manufactured by inequities. As residents sought to alleviate their pain through drugs; some providers sought to alleviate the moral-professional dilemmas created by the disjuncture between their desire to help, the limits of health services, and the magnitude of residents' suffering through practices that were experienced as coercive and intrusive. I noticed that providers who were often the most accepting of residents' decisions to decline treatment had *non-health care* backgrounds. These providers were not conditioned to see residents' behaviors as direct measures of their professional competence or adequacy as employees; they helped where and when it was requested but understood that self-determination was central to sustaining relationships and to residents' well-being. Providers who did not have backgrounds in health care viewed their health care

roles within the broader context of residents' lives rather than seeing residents' lives and roles in the context of medical priorities.

None of the nursing positions I had held prepared me for the intensity of residents' suffering, nor for their innate gifts, courage and fortitude. I realized how easy it was to lose sight of resident's agency when I started caring for residents as persons. As I became close to two residents in frail health, imagining the prospect of their death distressed me. I had been criticized by one resident for 'over-caring' and, while I wasn't working as a nurse, my relationships and understandings of care were no less conditioned by my affinities as a nurse and my desire to help. Thinking about a resident I had grown to love in a quiet moment one day, I found myself momentarily free of the angst that usually came when thinking about the fragility of her life. In that moment, I viscerally knew that over-concern was fueled by fear and that our lives had independent trajectories toward life beyond death. It was not my place to worry or fret. In fact, it was ridiculous and absurd. She had her own understanding of and relationship to life, as did I. So much health care, it then struck me, was an attempt to control fear about the inherent uncertainty and unpredictability of life. In that moment I *knew* in a deep way I had never felt before, that our lives were part of something that transcended the limits of our imaginings and control. It was OK to let go and let people be. In fact, it was all we ever *could* do – the illusion was thinking it was ever otherwise. As I've reflected on this moment, I also see over-care can be fueled by grief, feelings of inadequacy, yearnings for connection and recognition, and settler-guilt which may speak to the diffuse impacts of colonialism in providers' lives in a yearning for the moral redemption of self through others.

The colonial condition involved making their business 'our' business, but what did this mean in a context where the social conditions of residents' suffering were outside the purview of health care? A few residents complained that when they needed help all they got were a lot of 'words' or 'sympathy' and concluded that providers were not really interested in helping them change their lives. What two male residents who expressed such sentiments wanted more than words, I believe, was for providers to recognize their intellect, capabilities and agency *as different but equal* to those of the provider. As I describe in Chapter 9, when one Indigenous resident subsequently experienced this with a physician, it did not change the social conditions of his suffering, but it had a significant impact on his self-esteem, self-care and openness to health information. Numerous

times I witnessed the positive impact on a resident when they found a physician whom they felt liked and respected them as a person. It didn't change the inequities of their lives nor remove their struggles, but it offered a refuge where, for a few moments, they could relax their vigilance and fears and express themselves.

Thinking of the importance of self-determination for many residents, I recalled my own longstanding struggle to push back the relentless tsunami of well-meant 'help' from a family member who passed away while I was working on my dissertation. When a stroke effaced her intensity I was able to see her intellect, humour and delight in life, untainted by the vigilance that had, until the stroke, defined my relationship with her. Wondering how I could have missed 'seeing' her for so many years, I realized that all my energy had gone into keeping 'help' at bay. By reducing her intensity, the stroke had allowed me to be present and for us to interact in a new way. It struck me that many residents might be describing something similar in their relationships with providers. When there was spaciousness in the encounter, they could relax their vigilance towards authorities and begin to consider what the provider was saying. Only when providers suspended their efforts to change could residents suspend their systems of defense. Only then did change become possible because the residents' agency and vitality were restored as the context and core of care. In many instances then, it was respect for residents' readiness and right to self-determination, not the therapeutic aims of encounter, that were the catalyst for health.

## **6.2. Professional boundaries, time, norms and moral aims**

In the introduction to this chapter, I explained that providers' boundary discourse was selective: It drew attention to the socio-affective and political aspects of boundaries but not to their temporal, normative and moral dimensions. The temporal dynamics of care communicate power by requiring residents to bring their lives into alignment with service schedules. While many residents managed to do this, I found that the temporalities of care were not the only temporalities that informed their lives and on occasion, the temporalities of care collided with other temporalities of residents' lives. Prevailing conceptualizations of 'professional boundaries' could generate conflict between the temporalities of health care and of residents' lives in two ways. First, when providers' transgressed residents' boundaries, temporal conflicts sometimes manifested

in something I refer to as 'suffering time'. Second, the moral aims of care which imbued therapeutic temporalities, often transgressed residents' boundaries by ignoring the importance of their embodied readiness for change. The therapeutic temporalities of care, with their prioritization of physical health and longevity, were often incommensurable with residents' prioritization of readiness and health as a current state of well-being.

### **6.2.1. Colonial temporalities of health care**

Health care is predicated on a chronological understanding of time, organized in linear categories of past, present, and future. Consideration of patients' histories is often limited to the extent specific signs, symptoms or experiences are deemed relevant to the delivery of care. Providers' practices are assumed to exist in 'the present' with the moralities of care linking the present to anticipated benefits for future health. Given the prominence of scheduling and efficiency in most health care settings, and in the Clinic discussed in Chapters 7 and 8, I refer to these two interrelated expressions of chronological time as 'clock time' and 'therapeutic time'. Clock time is measured in increments as reflected in hours of service, providers' schedules, and funding cycles. Therapeutic time links present actions to future outcomes and incorporates providers' assumptions of which kinds of futures are possible and desirable (Jain & Kaufman, 2011).<sup>43</sup> These temporal aspects of care are related to capitalism and colonial dynamics and inform and are expressed through the establishment of professional boundaries.

Chronological time was naturalized in Western societies in the early 19th century with the industrial need for a disciplined work force and the synchronization of production processes (Klingeman, 2000; Zerubavel, 1982). The industrial influence continues to pervade health services with the emphasis on efficiency and outcomes. Chronological time also imbued 19th-century racial sciences, with Europeans' belief that Indigenous Peoples lived in a primordial past. The colonial mission to civilize sought to bring Indigenous Peoples 'into' the present by inculcating an industrial temporality associated with regimentation and productivity. The morality and telos of civilization and

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<sup>43</sup> An examination of Indigenous Peoples' temporalities is beyond my analysis of the temporalities of health care interaction but the literature that I reviewed for this study indicates that Indigenous temporalities are diverse. For example, the present-future orientation of care also informs the work of some Indigenous healers (Waldram, 1997) and Stevenson (2014) found that with Inuit naming practices, the past, present and future are contiguous.

assimilation, as discussed in Chapter 2, is reproduced in the morality and telos of health care.

In the last 15 years, there has been more critical attention to patients' histories and trauma, and how prior exposures to violence, abuse, and social instability can influence patient behaviors in the present (Fassin, 2007, 2011; Million, 2013). In her detailed ethnographic analysis of the Canadian Truth and Reconciliation Commission (TRC), Million (2013) examined how the medicalization of 'trauma', in portraying Indigenous Peoples as fundamentally harmed, undermines their political aspirations of self-determination. By giving more attention to patients' histories, 'trauma-informed' approaches to practice produce a temporal dissonance in health encounters between the acknowledgement of the patient's trauma (where history lives in the present) and the presumed ahistorical health encounter (where the provider interacts in the present). Like the 19th-century mission to civilize, the provider aims to bring the patient more fully into the present as a basis for realizing improved health in the future.

The normative and moral dimensions of therapeutic time, which are reflected in providers' understandings of health, health problems and what kinds of changes are desirable, are assumed to be shared. This fails to consider how multiple temporalities, norms and moral aims may coexist in health care relationships. Thus, when the associated temporalities and moralities of a health care encounter come into conflict, the harms that occur are rendered invisible to providers; as illustrated by the example I share in the following section.

### **6.2.2. Suffering time**

While residents adhered to agency schedules when accessing care, the temporalities of their lives were also influenced by the exigencies of street life, drug use and suffering. Many residents told me they lived day by day. It was a rational response to the unpredictable realities of street life. When interacting with friends, one resident said, 'you never know if you'll see them again' (Interview, 1 September, 2009).<sup>44</sup> Drug-use also influenced residents' sense of time. Some residents said that street drugs caused time to 'speed up' or 'slow down' – findings also reported by Klingeman (2000)

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<sup>44</sup> Lovell (1992) also noted the fluidity of street life among homeless people.

and Connors (1994). More often, residents stated that drug use numbed their feelings and kept thoughts of the past and future at bay. In this way, drug use created a contingent present. Residents' past exposures to violence, abuse and loss also impacted their sense of time but it tended to remain unseen until, as shown in the following field note, a nurse, 'Cheryl', violated the resident's boundaries in the pursuit of 'care'. The resident, 'Maggie', was a frail, older Indigenous woman.

While I visited with Maggie in her apartment one afternoon, Cheryl from [the Drop-in] arrived to deliver a medication, but Maggie refused her entry. Knowing I was inside, Cheryl called me to the door and asked me to administer the medication. I was unwilling to do this but felt morally caught between her urgent warning that failure to receive the medication could cause a stroke, my relationship with the Drop-in Centre and my relationship with Maggie. In response, I persuaded Maggie to let Cheryl in and the medication was administered. However, after Cheryl left Maggie expressed how angry she was – not at me, but that I had been 'used' to get to her. It was an intense situation, but I had betrayed her wishes and the sanctuary of her home and regretted my actions. The next morning, I was again with the Maggie when Cheryl returned to administer another dose of the medication and entered through the apartment door which had been left ajar. Once again, Maggie clearly stated she did not want the medication. In an effort to elicit Maggie's consent, Cheryl cited the risk of stroke if the medication was not taken. When this warning again failed to have effect, Cheryl switched tactics and stressed her concern and care for Maggie, causing her to explode in fury '*where were you when [authorities] were abusing me!*' As I encouraged Cheryl to relent, Maggie ordered her out of the apartment. The use of 'care' to overpower Maggie's resistance in the present called forth memories of another authority who had deployed 'care' to overpower her resistance in the past. In that moment the affective intensity of the past fused with the present (Field Notes, 28 and 29, June 2011).

Maggie was enraged for weeks afterwards and her relationship with Cheryl was permanently damaged. Cheryl's predictions of dire harm and the use of coercive practices to promote health were belied by the affective harms of her actions and by the fact that the physician discontinued the medication the following day.<sup>45</sup> Maggie referred to the incident as her 'home invasion' and up to her death several years later, had not forgotten nor diminished its impact.

This observation and similar accounts by other residents indicated that, when providers' actions were reminiscent of the harmful actions of earlier authorities, the affective force of memories could overwhelm the residents' capacity for self-control.

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<sup>45</sup> I later learned that the nurse's main concern was that I had undermined the delivery of care.

Whether providers realized it or not, their practices were situated in the history of various authorities' responses to resident and thus became part of their current interactions with residents.

As I became familiar with several residents' backgrounds and observed their responses to providers in various situations, I began thinking of embodied memories of abuse as emotional landmines that lurked below the surface until a provider's actions 'tripped the mine'. The subsequent response revealed an embodied temporality of suffering where the resident's memories and affective responses of past harms momentarily fused with the present. The temporalities subsumed in professional boundaries are important because it is often providers' practices that precipitated suffering time. Although these affective-temporal ruptures were not unique to Indigenous residents, most of the instances shared with me or that I observed involved Indigenous residents. I attribute this to the fact Indigenous residents were more likely to have been wards of state institutions, such as foster care and corrections, and therefore had more exposure to systemic discrimination, authorities and related harms. Indeed, only one settler resident reported being placed in institutional care as a child (foster care, then juvenile detention), while this was commonplace for Indigenous residents.

Suffering time could become operative when providers transgressed residents' boundaries as in the example above or as a result of statements or actions that, to the provider or an observer, could seem unremarkable. A few residents described having dramatic responses to the 'no word'. 'Just these little things', one Indigenous resident explained could take him 'back to the ordeal. . . . My frustration kinda' builds up and I just blow my steam, things come out of me – I don't even hear myself saying (Interview, 1 April 2011). The clearest explanation of suffering time was provided by the following Indigenous resident who grew up in various forms of institutional care:

Res: I can't handle it very good when people start telling you, 'you gotta do this, you gotta do that'. No, you don't, I don't have to do none of that and then I rebel. . . . Everything just falls in, right from the foster parents, to the guards in jail, cops, everything. *Everything* just starts coming together like that and I just [voice and emotion rising] – '*Fuck you guys* man! I'm not going to do nothing!' [The resident held his arms far apart in front of him and rapidly drew them together, gesturing how differences between authorities fused into one]. Everything just falls right into place and everything just draws

in together and it's not good. And then this little red thing, starts getting bigger and bigger and bigger.

LC: What's the red thing?

Res: That rage.

LC: You actually see red?

Res: And that's when you get to the black-out stage. You don't know what you've done. That's the scary part . . . sometimes all those childhood things they come together and you can't help, it just happens – you want to fight everything off, forget everything, but you can't because somebody keeps bringing it back up (Interview, 1 April 2011).<sup>46</sup>

Tunnel vision, blacking out and 'seeing red' when pushed beyond their capacities for self-control were reported by several residents. But temporalities suffering were not always so dramatic or obvious. When I complimented one resident on her charm, she said the word always caused something to flash across her mind; it was gone before she could grasp it, but the feelings that lingered were bad. I found two residents, whose parents' behavior alternated between torture and gross neglect, often conveyed a sense of immobilization in interviews and casual conversations.<sup>47</sup> As children, they were damned if they did and damned if they didn't, always uncertain when violence would erupt again. This sense of immobilization not only reverberated through their interactions with me but was also present in their interactions with providers.

One resident frequently mentioned wanting to do something (i.e., cleaning up or investigating a medical concern) then would just as quickly add why it wasn't possible (i.e., he was too old, or it would interfere with his morning routine). It was evident in the following example where he expressed concern about losing his teeth. Early in the interview he told me his First Nation band would cover the full cost of dentures. When he mentioned it again toward the end of the interview (in the following excerpt), it became apparent that his concern for his teeth represented a deeper personal struggle when addressing his health care needs.

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<sup>46</sup> I found many residents disliked talking about their past because it evoked painful feelings and, some believed, brought bad luck.

<sup>47</sup> My conceptualization of how the past-present fuse in 'suffering time' contrasts with Das (2007) and Langer (1997) who found when research subjects recalled life-threatening violence, their narratives seemed 'frozen' in time.

Res: My teeth is falling out because of all the drugs I've done . . . my band pays for all my medicine and everything.

LC: Were you wanting to get your teeth looked at?

Res: I might be doing that Monday. That's why I don't do stuff like that, fix everything up because I don't want to waste my band money . . . because I might be gone next year or something.

LC: You could be around for 30 more years and then you'd have a beautiful smile.

Res: And then I could not be [here 30 more years] and I could just be wasting money (Interview, 20 June 2010).

It seemed that his history held the present and future captive, just as someone had held him captive as a child. In these situations, residents' histories froze therapeutic time in a historical present where the meanings of providers' responses were even more uncertain.

### **6.2.3. Therapeutic time and readiness**

Therapeutic temporalities of care could also transgress residents' boundaries in the tacit moral assumptions about the desirability of improving health and how health itself was defined. The idea of change implies a future, but understandings of the future can carry positive or negative associations (Crapanzano, 2007). The uncertainty of many residents' lives made it difficult to think about the future. Some had little reason to hope that the future might be any better than their past or present. One resident, for example, refused to set goals on the basis it would feel like tempting fate and setting himself up to fail. His reluctance to plan wasn't a product of negative thinking but a rational response to the uncertainties, perceived failures and suffering that had characterized his life. I observed two residents, during periods of relative stability in their lives, enroll in classes to upgrade their basic education only to have their lives soon thrown into disarray by events beyond their control.

It was not that residents *didn't* think about the future but rather that the future they considered was often focussed on the super-near. Some talked about the need to 'stay 10 steps' ahead of others, anticipating the moves, countermoves, and consequences that might flow from their actions. This strategy, I might add, was also employed by a few residents to negotiate the uncertainties of health care relationships.

This foreshortened future reflected the level of stability residents felt in their lives and how far they could confidently imagine 'stepping' beyond the present. It conferred a semblance of control while expressing just how little control many actually felt.

Therapeutic temporalities of care were exemplified by the promise of ARVs (Jain & Kaufman, 2011) for significant improvements in residents' physical health and longevity. Providers did their utmost to encourage residents to take the medications and frequently broached the topic of adherence with those who were already taking them. In some cases, these reminders were incorporated into playful, rehearsed exchanges that symbolically affirmed their relationship. For many others, providers' efforts often left them feeling frustrated, controlled, harassed and occasionally alienated from their care. As one resident shared:

I can hear them pushing – not me, but other people. It's not right. They're pushing them away, more likely . . . they want to make them [residents] take their meds and some of them, they're not ready. They're just not wanting [to] because they're doing too much drugs and drinking. They shouldn't push them. It will . . . push them more down the street. Like let them come in when they're ready (Interview, 30 April 2010).

Many residents, and Indigenous residents in particular, talked about the importance of one's readiness for change. Readiness was an intuited state of being that could not be predicted or externally managed. It was not so much that feeling one's pain, was the necessary catalyst for healing (a view held by some providers and residents) but that self-determination and learning through self-discovery were central to life and well-being. The following comment by an Indigenous resident reflects this:

If they're going to miss a day, let them miss a day. Teach them with the pills; . . . you're gonna get sick eventually if you don't take them. Because you know how you feel right? And if you're going to start getting sick, then you're going to realize in your head, 'hey! I need those meds' (Interview, 20 March 2011).

Reinforcing this perspective, another Indigenous resident explained:

Just let that person be; . . . if the person doesn't [die] . . . eventually they'll come around. And then that person will think different after that; . . . they're going to come back and their head is going to start clearing a little bit, and they're going to ask themselves 'what the fuck am I doing' and they'll come around on their own (Interview, 1 April 2011).

Just like providers' who only started to understand professional boundaries when they became emotionally exhausted, it was only when some residents' health declined that they became receptive to ARVs. While several providers recognized this, it underscored the importance of embodied knowledge; learning from experience.

Where providers were compelled to spare suffering and save physical lives, the role of a helper, according to several Indigenous residents, was to guide people to their *own* understanding of what was right and true. An Indigenous resident demonstrated this in his approach when helping others, 'I never preach at them, I never give them shit. I kind of givem' something to think about . . . the choice is theirs to make' (Interview, 13 April 2010). He, like many other residents, shared that receiving the news of being HIV positive spurred a prolonged period of intensive drug use. Without daily outreach to deliver his ARVs this resident thought he would have died. It wasn't that he'd wanted to die at the time and he was glad that he had survived, but even years later he remained 'a little pissed off' at the providers who delivered his medications. He still believed providers should have 'just let me be' (Interview, 1 April 2011). The possibility of an earlier death did not trouble him because '[having] no choice; I think that's worse' (Interview, 1 April 2011).

The phrase, 'just let the person be' surfaced in several Indigenous residents' interviews over the course of fieldwork as advice to providers. Biomedicine addressed physical health but could not address what made life worth living nor could it create the internal motivation needed to sustain change amid the realities of street life. The problem, one Indigenous resident told me is, '[providers are] only taught one thing . . . the spirituality part is not there, so there's a disconnection' (Interview, 7 April 2011). When I interviewed an Indigenous Elder who was known for his work as a traditional healer, he talked about the need for people to respect the spirits of illness. Fighting and resisting illnesses such as HIV, he told me, would cause the disease-spirit to tighten its grip on the body. Echoing Indigenous understandings of personhood discussed earlier, well-being for this Elder resided in the restoration of the relationship between the physical, emotional, mental and spiritual dimensions of one's life. The key to health, he said, began with loving oneself, loving where you came from and cultivating gratitude and respect for life in *all* its forms. Although physicians' tried to delay starting patients on ARVs until they were 'ready', the ability to respect readiness varied with the status of their HIV infection. Once started on ARVs, as I discuss further in Chapter 8, a readiness-

centred approach was often at odds with the science and therapeutic temporalities of medicine which found that the inconsistent use of ARVs increased the chance that patients would develop treatment-resistant strains of HIV.

Therapeutic temporalities of care could transgress residents' boundaries and temporalities in another way. One Indigenous resident explained providers' repeated questioning about HIV and reminders to take her medication left her feeling 'stuck' at the time around diagnosis. Another, who also found providers' emphasis on HIV a strain, said 'it just brings me down and makes me feel I got to go do a hoot<sup>48</sup> just to get away, just to forget about it' (Interview, 20 April, 2010). 'Moving forward', in terms of living with HIV, meant being able to forget. Health came through enjoying life in the present. As the following Indigenous resident, Denno, explained:

Res: Just the thought of the disease [HIV], nobody wants to talk about it period. I think that's the bottom line, that nobody wants to talk about it, nobody wants to hear about it, nobody wants to say . . . you know, 'I'm infected' – they just want to forget about it. . . . The last thing you want to hear about is your health. . . . I live with it day in day out and the less I hear about it, the less I have to worry about it [the better;] . . . it's like a hamster in that little wheel . . . [when providers keep reminding you] the noise gets louder and louder. . . . And that's maybe why people commit suicide because it's just too loud; they can't take it anymore.

LC: So when you think about your life – what things do you like to focus on?

Res: I'm a jokester, I'm a people person and I like to make people happy and smile. And when I do that, it brings me up. I like to swim I like to ride my bike. I think I just like to live (Interview, 7 May, 2010).

Denno was not 'against' health care: He recognized his life depended on ARVs, but for him well-being lay in accentuating the powers of life in the present – vitality not sickness.

Residents didn't decline help because they thought their lives were satisfactory or that they had no desire to improve, but rather that their health was *their* issue and they would broach it (or not) when ready. The tension between providers' desire to improve health and their ability to respect Indigenous Peoples' self-determination has also been documented by others (Kowal, 2008; Lea, 2008). It wasn't unique to providers.

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<sup>48</sup> A 'hoot' refers to smoking crack.

One Indigenous resident who found his brother hospitalized as a result of not taking his ARVs, told me how angry he felt about his brother's lack of self-care. To paraphrase Stevenson (2014), is it possible for providers to articulate their 'desire for the life of another without making that desire an imperative – without . . . demanding that he or she cooperate in assuming [the providers'] desires?' (Parenthesis added, p. 17).

### **6.3. Conclusion: Boundaries, suffering, and health care alliances**

*It [seems] to me that the stricter you keep those boundaries, the less engagement you get and the less influence and the less trust and respect you get too. . . . You're not their friend but you have to also on some level feel their feeling, and feel their fears, be able to address that and hear it to be able to have their trust to guide them in a way that will be helpful. (Physician, Interview, 7 May 2010)*

It is undeniable that closer, more personal relationships held the potential to harm residents *and* providers. Aside from the harms produced by transgressing residents' boundaries, harm could result if the resident was attached to a provider who became ill, retired, or moved to another job. I observed how the departure of one provider devastated a resident. I also witnessed how the relationship had carried the resident through a series of critical events during two years of fieldwork. The same resident reported feeling 'a little bit' abandoned by my departure. She understood 'the reasons' and said she 'forgave me' because I kept in touch, but emotionally it reinforced the broader reality of her life where all relationships were uncertain.

Despite the risks, challenges and points of tension in the preceding critique of professional boundaries, many warm and supportive relationships did occur. These 'health care alliances' signify relationships that were characterized by mutual positive regard, a level of trust, affection and ease in the interaction. In most alliances, the resident's interactions with the provider did not extend beyond the hours of service or the parameters of the provider's role. Some residents described providers in these relationships as more like a friend or (in a few cases) like a parent. Others described providers as interacting like 'a normal person', or creating a space where residents felt treated 'like a normal person'.

When I subsequently told a few providers that some of their clients described them as friends, most providers immediately recoiled. For example, one replied: 'This is my job. We're not friends. I only know the people I know because they're my clients. We're not friends and we won't be friends. We can't be friends' (Interview, 18 September 2009). I later learned that the provider had received negative attention about her boundary practices, so I attribute the vehemence of her response, at least in part, to her sensitivity around that issue. A physician reported feeling 'a little bit uncomfortable' that some patients' considered him a 'friend' but said if 'friend' meant: '[The doctor] respects me, I feel I'm comfortable with him, I feel I can speak openly, that [he's] competent, that he has my best interests at heart, that he motivates me . . . if the term friend means I'm doing those things, that's great' (Interview, 19 April 2010). This was the gist of what residents intend by 'friend'. In the two worlds of the DTES, with its prevailing categories of provider or resident, referring to a provider as a friend was a compliment and a way to express how their relationship did not reflect the residents' conditioned experiences of interactions with authorities.

Despite some providers' reaction to being considered 'a friend', several providers did maintain close relationships with residents across agency, public and domestic spaces. For example, some providers had residents regularly dropping by their offices to visit, while others introduced residents to family members and attended social functions together. Some residents introduced providers to family and invited them to personal functions. One resident called out 'I love you' when leaving a provider's office with the provider responding in kind. Another provider regularly visited several Elderly Indigenous residents and at Christmas stopped by after work to help one decorate his apartment. These were honest, heartfelt expressions and moments of care and underscore the diversity in health care relationships, where some relationships weren't personal or professional but a bit of both. In these relationships the provider was still aware of their role and the asymmetries in power but was also committed to the resident as a *person* irrespective of changes in their work-roles or sites of work.

To condemn close relationships that sometimes formed as 'boundary violations' would violate their essence and deny the medicine of relationship (Stevenson, 2014). Indigenous scholars have acknowledged that the relationship is central to many Indigenous approaches to healing (Graveline, 2004; Maracle, 2005). However, as Million (2013) notes, the importance of relationship for Indigenous Peoples is based on an

understanding of life that celebrates strengths and diversity. The medicine of relationship thus draws from the power of personhood, rather than one's training or role. As such, it is not exclusive or unique to providers but is also possessed by patients. Frank (2004) explains that when providers respond from their personhood they recognize the patient as a person and view their suffering as a moral rather than technical or medical problem. The generosity expressed in these encounters, according to Frank (2004) and reinforced by my own observations, contributed to a re-moralization of care for the resident and affirmed providers' ongoing efforts to address residents' suffering. As I discuss further in Chapter 9, I contend that health care alliances exemplify the power of personhood and illuminate the medicine of relationship. The opposite of alliances were interactions that residents described as encountering 'a wall', where the hierarchies of power, professional boundaries and the providers' priorities were experienced as rigid, distant and/or indifferent.

I contend that the emphasis on boundaries in this setting is a response to the equally important emphasis among providers of developing relationships with residents. This produces constant tension in providers' efforts to maintain distance while cultivating health care relationships. Although professional boundaries were important and helpful in many respects, they were based on a number of problematic assumptions and often enacted harm by failing to consider residents' boundaries. I found that one of the main functions of professional boundaries for providers was to protect them from the risks of relationships with residents. Although boundaries presume that the delivery of care occurs in a therapeutic present, I contend that providers' actions are always interacting with residents' histories and elaborated this through my concept of 'suffering time' and residents' notion of 'readiness'. With this, I argued that when providers prioritize the therapeutic aims of care over residents' ability to self-determine, they may actually destroy the conditions needed to support change.

The next three chapters show how providers' interactions with residents are shaped by the structures, purposes of their roles, and wider context of health care in the Clinic. I illustrate that colonial dynamics are enacted and how the power of personhood takes shape in each setting.

## Chapter 7. Clinic reception area

I now turn attention to examining how colonial dynamics were enacted in the medical Clinic. I focussed my fieldwork on the public area of reception (covered in this chapter), and the private areas of physicians' office-exam rooms where medical interactions with residents took place (covered in the next chapter). There are two parts to this chapter. In the first, I introduce the Clinic describing the two main groups of providers and discuss dynamics that pervaded the Clinic. In the second part, I examine the specific ways that colonial dynamics were enacted in the Clinic reception which included the work area for staff and the waiting area for residents. I explain how staff enacted a two-step process of 'filtering' that brought residents' need for services and their behavior into alignment with physicians' availability and behavioral norms of the Clinic. I argue that staffs' definition of 'problematic behavior' was often produced by the structural, temporal and normative constraints of their roles which limited their ability to interact with residents as persons and, in many instances, intensified the potential for conflict.

### 7.1. Introduction to the Clinic

*We're very proud of Native Health – I think the whole staff feel that . . . we feel good about where we work and we want to share that [with] people.  
(Provider, Interview, 5 November 2009)*

The Clinic was staffed by reception staff, physicians, the clinic manager and the clinic nurse. When referring to all Clinic personnel I use the term 'provider'; otherwise, I differentiate 'physicians' from reception 'staff'. I sometimes identify staff by their specific roles as intake workers or medical office assistants (MOAs). Like other medical clinics, an occupational hierarchy based on differences in providers' education, status, and remuneration, created asymmetries in power that were apparent in physicians' having more influence over their work, less exposure to noise and interruptions, and greater freedom to interact with residents as persons.

The formal structure of the Clinic included two key administrative positions. One was the clinic coordinator (more commonly referred to as the Clinic's medical director), who represented the Clinic in meetings, set strategic goals and had overall responsibility

for administrative matters. The other, was the clinic manager who was the official communication bridge between staff and physicians. Her responsibilities included translating the clinic coordinators' vision and strategic directions into practice, administering day to day operations and staffing, and representing the concerns of staff at medical meetings. Although the individuals in these positions had very different educational preparation and functions, by virtue of their roles, their shared values and relational approach became encoded in the organizational structure of the Clinic and nurtured these tendencies in relationships among providers and between providers and residents.

My analysis found that across the Clinic colonial dynamics were enacted through the industrial temporalities of care, the prioritization of medical care and the related support functions needed to sustain the flow of patients through the clinic. The Clinic's prioritization of these is to be expected, what is important here is how these dynamics structured relationships and interacted with beliefs about the potential dangers of Addicts. I found these beliefs surfaced when residents' behaviors or needs were seen to pose a threat to safety, order, or the flow of patients through the Clinic, and when residents behavior touched on areas where providers' authority, knowledge or ability to respond were limited.

Numerous factors contributed to maintaining beliefs about Addicts such as residents who sought prescription drugs for non-therapeutic purposes and fights between residents that occurred on the sidewalk outside. Occasionally these conflicts spilled into the Clinic. For example, one afternoon a man entered and collapsed on the reception floor with blood dripping from a gash on his head. Such instances were infrequent but nourished stories of residents' potential for violence which circulated among providers and created an ongoing vigilance to identify and manage signs of potential danger. Several providers told me about computers being thrown across the room, of knives being pulled, and of residents threatening to 'get' them after work. Only one was a first-hand account that had occurred in this Clinic. These stories preyed on some providers' fears for their own and others' safety. 'If I had to say no to somebody about something they want' one physician explained, 'there's always this concern [of retaliation], especially in the winter time when it's dark, I don't leave out the back door' (Interview, 30 April 2010). I recognized how anxiety could build over time through

ongoing interactions with residents.<sup>49</sup> I also witnessed the intensity of one resident's rage so did not question the fear this could evoke for providers. However, I argue that the behaviors associated with Addicts were also *co-produced* by Clinic structures, the influence of colonial dynamics in the broader context of health care (such as external regulations of physicians management of chronic pain), and providers' practices. Health care encounters were thus predicated on a double-standard: Providers' worked to cultivate residents trust in them, while often simultaneously believing and behaving in ways that presumed residents would not be truthful, or interpreting and responding residents behaviors in ways that reinforced these beliefs. This resulted in contradictory affective currents that residents often had to overcome to access care, and that providers had to reconcile in order to maintain the delivery of care.

Both parties perspectives were limited by their social realities and position in the hierarchical structure of medical encounters (Haraway, 1988). For example, residents critiqued providers for 'just being in it for the money' without seeing how often providers started work early or worked through lunch to accommodate additional people. Similarly, providers hastened to quell any behavior seen to signal the dangers of Addicts, without realizing the broader stress of residents' lives and how their practices could elicit or exacerbate conflict.

In earlier chapters I discussed the interplay between colonial dynamics and personhood, and how providers' personhood could intensify and temporarily mediate residents' experiences of the hierarchies of care. Although I discuss the 'mediating' effects of personhood in detail in the final chapter, to reflect the interplay between colonial dynamics and personhood, it is important to include some references to the warmth of everyday interactions with my analysis of the reception area. In this way I hope to set the general tenor of provider-resident encounters for the next chapter as well.

## 7.2. Reception: Waiting to be seen

*A male resident tells me the front office staff feel more like friends – he knows them all. It's not like [the other clinic] where you're given a number*

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<sup>49</sup> As I learned how some residents staged break-ins to peoples' homes and cars, there were times toward the end of fieldwork where I felt anxious leaving my home or car unattended.

*and staff put on their 'business-only' face. (Field Notes, 3 November 2009)*

Upon entering the Clinic's cramped and noisy reception area, one was greeted by an intake worker seated at a desk facing the front door. The first point of contact for most residents, intake workers booked drop-in appointments, triaged concerns and were responsible for maintaining order in the waiting area. On the west wall, a door opened into a hallway that led to a office, a public washroom and the Drop-in Centre. Against the front window, which spanned the waiting area, residents sat on chairs dozing, interacting with each other, or staring blankly ahead at wood and glass-topped partition that separated the elevated work area beyond. There, three to four medical office assistants (MOAs) sat little more than elbow distance apart at a common desk answering phones, completing dictations, and entering data into computers. Their work was subject to frequent interruptions from physicians, allied providers, visitors and residents' seeking information. Behind the work area, a hallway led to the back door, connecting an area for medical records, physicians' and the nurse's office-exam rooms, the clinic manager's converted closet-office and a staff washroom.

Providers in reception served as the interface between medical care and the street; their work supported the flow of residents through the Clinic. Staff positions were gendered – all intake workers were male, and all MOAs were female. One MOA, who sat facing the waiting area, helped manage residents' behavior, and when intake workers were not available, temporarily filled that role. The smallness of the space forced a degree of intimacy. And stability in staff created a sense of familiarity that many residents said facilitated their access to care.

In interviews, staff often commented on the positive work environment of the Clinic. Unlike the rigid roles and negativity several staff had experienced in unionized environments, here they had input into decisions and a shared sense of purpose. As one provider explained;

Everyone is very genuine . . . every [provider's] personality is very different but everyone has one goal and that is to treat people [with] the most dignity and respect. . . . There's more of a family feeling [and] it's inclusive of the clients. . . . It allows you to feel you have the freedom to care for people in your own way' (Interview, 4 February 2010).

When I asked one staff member what contributed to this, she replied: 'We're all accepted for who we are and that [respect for our] individuality – it gives us self-confidence' (Interview, 10 November 2009). It was also characterized by the spirit of cooperation: 'If you see something that needs doing', another explained, 'you do it. I change light bulbs, I fix toilets, I sweep the floor – whatever needs doing, you do it' (Interview, 5 November 2009). Open communication among providers affectively tempered hierarchies in their professional status and roles. When a physician's response to a resident left a provider in reception feeling undermined, the provider expressed herself without hesitation, fear of sanction, or the need to channel the concern through her supervisor.

For several staff, working at Vancouver Native Health Society (Native Health) was their first experience in the DTES. A few recalled feeling uncertain when they started their jobs, but through interactions with residents started to recognize and admire them as persons:

You hear about the DTES on the news and it seems like a cold, dark, ugly place for people, totally dysfunctional. That's from the outside looking in, but once you're on the inside, it's not . . . there is a community here. I'm amazed at the tenacity of the patients no matter how sick they are. I'm amazed at their will to live . . . when you respond to them and when you're interested in them and they'll come and tell you what's going on in their lives (Interview, 10 November 2009).

### **7.2.1. Filtering**

The number of residents seeking medical care usually exceeded the availability of physicians. Reception staff implemented a two-step filtering process that aligned residents' needs with physicians' availability and selected residents whose conduct aligned with the behavioral norms of the Clinic. I view the filtering process as colonial because it illustrates how the complexity of residents' lives and needs were made to fit a system of medical production that was based on an industrial temporality of care that was designed to promote efficiency and productivity by excluding surplus need and those unable or unwilling to conform. By describing how the Clinic structures, norms and temporalities shaped this process, I demonstrate how those same forces also constrained the work and responses of staff.

The first filter addressed residents' admission to the Clinic, which involved getting to the Clinic and obtaining a pre-booked or drop-in appointment. Pre-booked appointments were only available to regular patients of the Clinic and were usually assigned by physicians at the end of a previous visit for follow-up purposes.<sup>50</sup> The number of appointments each day depended upon the number of physicians working, whose time was divided into 20-minute appointment slots. The Clinic aimed to have no more than one-quarter of appointments pre-booked with the remaining three-quarters available for drop-in patients. Since physicians' booked appointments in response to the immediate needs of patients in their offices, occasionally it resulted in them pre-assigning most of their appointments which left less space for drop-in visits.

Drop-in appointments were assigned on a first-come first-served basis. Rain or shine, seven days a week, a line of residents formed along the sidewalk up to an hour before the doors were unlocked. As they entered the Clinic an intake worker handed each resident a number which corresponded to a medical appointment slot. 'The first-come first-served' approach sought to promote fairness, but preferentially selected residents who were able to line up early and wait. This excluded those who lacked the physical mobility or strength to get to the Clinic and wait in line, and those unable or unwilling to align their lives with the Clinic schedules.

Drop-in appointments were often fully assigned within a half hour of the Clinic opening. Once the Clinic was 'full', the main door was locked and those unable to obtain appointments were encouraged to return at a later clinic or try another clinic in the area. Locking the Clinic door spatially distanced staff from residents who were turned away but did not relieve the moral and emotional burden of staffs' desire to help, a sentiment also reported in other studies (Strathmann & Hay, 2009; Solimeo et al., 2016). One MOA explained: 'When patients can't see a doctor . . . you feel sad about having to say to a

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<sup>50</sup> There were two general avenues for residents to become a 'regular patient'. Residents who met certain criteria were eligible for immediate intake. These criteria were determined by physicians and periodically reviewed. During fieldwork they included residents who were either HIV positive, youth, or Aboriginal. Residents could also become regular patients if they had visited the clinic three times (T. Braun, Personal Communication, 4 October 2017). Given the heavy workload, when a new resident sought care, staff encouraged those with physicians at other clinics to access services there. However, since any resident could access medical services at Native Health on a drop-in basis and most visits required follow-up appointments, it wasn't long before someone was considered a regular patient. The Clinic aspired to have all regular patients assigned to a primary physician who assumed overall responsibility for their medical care; however since physicians also had to serve drop-in patients, the care of many regular patients was shared among physicians.

patient [that] we can't [take them]' (Interview, 10 November 2009). The MOA later added, "when I have to say to someone, that we can't take new patients. . . . I hate it. I hate it. Well, I've learned that we can't be everything to everybody. I've learned it, I know it in my head, but I still feel frustrated (Interview, 2 February 2010).

Residents' main critique of reception was the long wait times which often exceeded two and three hours. Providers attributed the long wait times to physicians 'giving residents the time they needed' and squeezing in additional patients as allowed. This flexibility was appreciated by the subjects. As one Indigenous resident explained: '[It] really helps . . . because sometimes you forget to get your prescription refilled . . . getting squeezed in. . . . makes you feel you matter or that someone cares' (Interview 20 August, 2010). But maintaining flexibility amid the structures designed to keep patients moving through the Clinic came at the cost of increasing the already long wait times for those remaining in the queue and added to providers' workload stress. For many residents, the long-wait times reinforced their experience of inequities and left some residents feeling that they were serving the system, rather than being served. One male resident, reflecting the sentiments of many, told me the long wait times made him feel that those running the Clinic thought he had nothing better to do. Accessing medical care often involved relinquishing opportunities to make money or meet other needs. As explained in Chapter 5, it represented one more service to line up for. When one male resident was asked if he'd be willing to let another go ahead of him, he hesitated and then explained he'd spent three hours that morning waiting in a line to speak with someone at the government welfare office and had already spent an hour waiting in the Clinic.

Some residents tried to circumvent wait times by pre-booking the first appointment of a clinic or being first in line. Several times residents arrived to find other patients had been squeezed in *before* the first appointment. The practices of other local clinics placed additional strain on the drop-services at Native Health. Several providers who worked at other clinics in the area reported practices that reduced residents' access to services, such as blocking off several hours each week for meetings or for staff to catch up on work; rigid adherence to hours of work; and physicians who filled their

practices with less challenging residents. One provider saw the latter as a strategy that some physicians used to manage their exposure to chaos.<sup>51</sup>

## 7.2.2. Behavioral regulation

*You can have the phones ringing, where the three of us can hardly cope, the doctors phoning that they need this and that, the patients are at you, and the doctors don't stop to think that they might not be the only one asking you for something at the moment. (Reception Staff, Interview, 2 February 2010)*

The second filter involved the monitoring and regulating of residents' behavior inside the waiting area in an effort to maintain a calm, orderly, and safe environment. The regulation of residents' behavior was authorized by a behavioral code introduced in the late 1990s by the medical director at the time. The code included a no-tolerance policy for threatening or discriminatory behaviors and a refusal to treat residents who were obviously high or intoxicated. Staff exercised discretion regarding the influence of substances and rarely intervened if the resident was not disruptive. The definition of 'threatening' behavior was often subjective and influenced by staff workloads, their limited ability to influence Clinic structures, and norms of professionalism. In this Clinic behavioral regulation usually functioned as means to manage residents' frustration with the long wait times, were expressed in frequently asking how long the wait would be, moans, loud sighs, muttered and overt criticisms of the Clinic's process.

Residents recognized that behavioral regulation was necessary. Small, crowded and noisy spaces created considerable anxiety for some residents and when entering such spaces, residents risked encountering those with whom they had grievances, drug debts or other conflicts. For women and sex-workers, this also included the risk of encountering men who had abused and/or propositioned them for sex. The loud and disrespectful behavior of some residents toward staff could also add to residents' anxiety and deterred some from accessing services.

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<sup>51</sup> In recognition of work-related stress and a lack of breaks, Native Health closed for an hour for lunch. While many providers often worked through lunch, the break provided a welcome reprieve for providers to relax and 'catch their breath'. When some staff proposed closing the Clinic one morning a week to catch up on work, physicians declined the request. This illustrated the asymmetries between providers and the tensions between the commitment to serving residents, workload challenges, and the desire to support each other.

Sympathetic to the problem of long waits, staff often gave residents an estimated time when the physician would be ready to see them, which offered resident the option of leaving and returning later, or would encourage those infected with HIV to wait in the Drop-in Centre next door until called by the intake worker. Some staff tried to pacify residents by encouraging them to 'be patient' or appealing to them with pleas like 'you know it's always like this'. In an effort to reconcile the challenges, one MOA often told residents, 'An appointment isn't really an appointment, it just means you're guaranteed to be seen' (Field Notes, 21 December, 2009). But this was beyond staffs' ability to promise: if physicians had to leave by a certain time those still waiting might be required to return another day. When regular patients could not complete the wait time due to frustration, anxiety or other commitments, staff offered to reschedule their appointment and, in rare instances, booked them into the first appointment of a subsequent clinic.

When efforts to calm, distract or cajole residents failed to have effect, reception staff often succumbed to their own frustration and started to personalize residents' behavior, experiencing it as harassment, intimidation, or what one provider described as residents 'using their emotions to get what they want' (Interview, 2 February, 2010). In the same way that staff personalized residents' behaviors when strategies to help were exhausted, some residents, taxed by the endless line-ups for services and agency rules, saw the responses of some staff as efforts to exercise power by blocking their access. As a result staff, were often in the untenable position of being experienced as oppressors, while having their desire to help constrained by the same structures that they were hired to maintain.

Concern for the safety of physicians, and particularly female physicians, who saw residents in the privacy of their offices, left staff feeling some responsibility for physicians' safety. In this regard, behavioral regulation informally 'vetted' residents before they saw physicians, and indicated that in this setting the emotional burdens of reception staff, noted in other studies (Solimeo et al, 2016; Strathman & Hay, 2009) was not limited to residents but was also created by concern for physicians. However, I found little to support the belief that residents' behavior in the reception might predict their responses to physicians. Since frustration was generated by the long-waits, I observed that it dissipated once they saw the physician. The only exception to this was one individual known to have significant mental health concerns.

Regardless, expressions of residents' frustration were construed as threats to the calm and order of the waiting area. 'Negativity', one staff member explained, spread quickly and it was best to 'nip it in the bud pretty quickly' (Interview, 2 February 2010). After silencing 'negativity', this staff member told me she would 'walk away thinking, OK, that shut that person up' (Interview, 2 February 2010). She later explained that with workload pressures 'I haven't given much thought at the time to think about how they feel' (Interview, 10 February 2010). Her comment underscored how the industrial temporalities and structures of the Clinic, limited the ability of staff to interact with residents as persons, and hence constrained the personhood of both parties.

When staff disciplined one resident they vicariously disciplined all others in the waiting area, reminding them of their subordinate status, behavioral norms, what others could expect if they too didn't conform. The public enactment of discipline, as mentioned in Chapter 5, often shamed and humiliated residents. In response, some residents, and particularly men, felt they had little recourse but to stand their ground and just as publically resist providers to maintain their status among counterparts. It was more important, several male residents told me, to maintain respect among their counterparts who they frequently encountered outside the Clinic, than to be seen as weak, which could compromise their reputation on the street and make them targets for victimization.

Staff responses to residents varied with understandings of their roles, their beliefs about residents, and stress levels. Across settings, I had observed that providers, who prioritized regulations and conformity in their interactions with residents, tended to define problematic behavior more broadly, enact discipline more quickly and encounter more conflict. While all providers encountered conflict at times, I found these providers' descriptions of residents included terms like 'vindictive', 'bullying', 'scam-artists' or likened them to children prone to 'tantrums' which conveyed a defensive or authoritarian approach to interactions. I found such terms absent among other providers who demonstrated strengths in their ability to maintain congenial relationships with residents. A notable example in the Clinic reception was an Indigenous intake worker (one of the few Indigenous providers at Native Health at the time). This intake worker readily interacted and joked with residents and, unlike relationships with other staff, several residents also referred to him by name. This intake worker's response to residents reflected his ability to imagine the pain of long waits within the context of residents' lives. As he explained to me in an interview:

My feeling is that the majority of our patients there are dying. They're dying. So why would you want to make it a boring environment for them to spend four hours of their precious life in a waiting room if you can entertain them as much as you can and enjoy life and you get the laugh. That makes a difference (20 October 2009).

Providers' perceptions of individual residents in specific contexts varied, but the ability to trace some providers' beliefs, responses and residents' reactions illustrated how one's beliefs could influence their interactions. However, the reception area also showed there is more than providers' beliefs at stake in relating to residents.

### **7.3. Complexity**

Numerous factors complicated staffs' interactions with residents and influenced the regulation of residents' behavior. These challenges were exemplified in one encounter involving an Indigenous woman, 'Tess', who had recently, after many years, left the area in an effort to change her life. Not being subjected to the same constraints as staff, I had the ability to interact with Tess outside Clinic visits and, as a result, formed a different understanding of her behaviors. Described by several staff as difficult, demanding, and rude, Tess typically arrived late in the afternoons missing her appointments and then complained about the long wait with loud sighs, critical comments, and repeated pleas to staff about how long it would be. Staff said they had 'bent over backwards' trying to help by offering Tess the first appointment at clinics on numerous occasions. Promising to attend these, Tess again didn't show up until late that day or another afternoon and the cycle would begin anew. One afternoon I sat with Tess while she waited to be seen. Her agitation, once again, soon escalated. I witnessed how challenging her behavior was for staff. The MOA, 'Irene', initially responded to repeated inquiries of 'how long will it be', calmly telling the Tess she needed to be patient, reinforcing that she knew what the Clinic was like, and how staff had tried to help by pre-booking appointments in the past but she hadn't shown up. Then, as Irene again offered to book the first appointment of a morning clinic, Tess stated that she didn't 'do' mornings and would only attend an appointment if staff could promise that she wouldn't have to wait. It was a promise that staff didn't have the power to make. When Tess asked if she could see another doctor, Irene declined, explaining that since the physician had called Tess in, she could only see him. Finally, pressed to the limits of her influence

and patience, Irene informed Tess that if couldn't control her behavior, she might be asked to leave.

The next day, Irene shared with me that she thought Tess's behavior was staged for my benefit as Tess had never before asked to see a different physician. Just as it had for Irene, Tess's distress pressed me to try and help. Knowing how quickly another physician worked, it was me who suggested Tess might want to see if another physician was available. Although I had some understandings of appointment processes, until then I had not heard about the category of physician-initiated visits and thought Tess might be able to see someone else. Unlike Irene, I did not think Tess's behavior was contrived: I had been struck by Tess's anxiety during two lengthy Clinic waits and in our interactions outside the Clinic. Through these interactions I had learned about the fears and anxiety that pervaded her life, relationships, uncertain health and future. Returning to the DTES for medical care opened her to a host of temptations and challenges that, with the fears surrounding her health and future, threatened to overwhelm her. Talking about her experience in the Clinic, Tess told me reception staff didn't understand:

what it's like to be hurting for that high, they don't know what it's like to feel the fear of that person who is looking at you . . . they don't understand that we need to be heard. [When] they're looking at me as a drug addict, they're judging me [as though] I'm just like that [an Addict], well I'm not! I'm a person who needs to be heard: I feel, I cry, I'm needing someone to hear my thoughts and feelings because I'm hurting, I'm jonesing<sup>52</sup> because I'm scared, because I'm scared of my health, my side-effects, or whatever! (Interview, 29 July 2010)

She told me that when she felt unheard, unrecognized and 'sloughed off', '[I think] you know what, you're not going to treat me like shit. No, I'm not going to put up with that shit and sometimes I lost it because I can't handle being judged and being treated like that' (Interview, 29 July 2010). Known to have a 'very complicated' medical and social situation, the resident had been assigned to a physician who took more time, often ran very late, and had to leave by 5:00 p.m. No one had ever asked the resident if she would have preferred switching to a physician whose hours of work or speed better suited her needs. And I later learned that physicians were not necessarily aware of the stress some patients' visits created in reception.

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<sup>52</sup> Jonesing refers to an intense craving for drugs.

Clinic providers recognized the importance of 'getting the right fit' between residents' preferences and physicians' style of practice, but this was difficult to implement. Some residents were restricted to seeing a particular physician as a result of previous infractions, such as threatening remarks, stealing prescription pads or perceived tendencies for 'drug seeking'. Some physicians had 'closed their practice', which meant they were unable to assume ongoing, primary responsibilities for any more regular patients. And, if a physician had a good rapport with a resident, there was little reason to think a change in physician might be helpful. Other physicians only agreed to take new patients who met certain criteria. With these caveats, it's important to recognize that Clinic physicians often assumed the care for patients that other clinics and physicians in the area refused to treat.

Just as disciplining one, disciplined all, staff responses to specific residents in the waiting area were often interpreted by observers as 'general rules'. Witnessing counterparts who asked to see different doctors and were declined, one resident concluded they 'weren't allowed' to change physicians. Several residents told me they were afraid to ask to see a different physician lest the first physician taint other physicians' view of them. Others wanted to change physicians but told me they didn't know 'how to go about it' or were afraid of hurting the former physician's feelings. Asking also invited the risk of rejection. I neglected to ask but wondered if residents were also afraid they might have to explain their requests to staff and/or physicians which could have been an unnerving prospect given their need for medical care. Yet, when a few residents who had been identified as problematic by providers, started seeing a new physician, the 'difficult' behaviors disappeared, diminished or an underlying medical concern was diagnosed.

## **7.4. Conclusion: Recognizing limitations**

Where the magnitude of residents' need for medical care was most visible was also where staff had the greatest constraints on interacting with and responding to residents' needs. Although residents' personhood was recognized by staff in some ways, they had little understanding of the broader stresses in residents' lives and their experiences of institutional governance. Reception staff are required to adopt a position of power over residents and are seen by residents to have more power than they

actually do. This creates tension for staff as they struggle with their desire to assist residents and keep up with their workload, while maintaining order and sustaining the flow of patients through the Clinic. The norms of professionalism intensify limits in the temporalities and structures of care by inhibiting staff from acknowledging the limits of their influence. I argue that affirming their desire to assist residents, with greater transparency in the limits of their power, holds the potential to affirm residents' personhood and locate the pain of waiting in the industrial temporalities and structures of the Clinic. Doing so offers additional information that may influence residents' behavior and acknowledges that, while both are positioned in systems with significant limitations, providers' regard for residents and their desire to help them is steadfast.

The scenario of the resident with the 'very complicated' set of medical conditions demonstrated that just as the source of the residents' stress was invisible to reception staff, so too, the emotional labor and constraints on reception staff could be invisible to both residents and physicians. Hierarchies in power and the contexts of care limit what each party is able to see and understand about 'the other'. Within the context of their practice, reception staff *had* tried everything to accommodate Tess. From my vantage, they had overlooked two critical possibilities: that Tess's distress was real and that her behaviors expressed a desire to be heard and recognized as a person. Failing to consider these left the structural and moral dimensions of care unexamined and effectively scapegoated her as the preoccupation with her behavior became the alibi for the stress of structural limitations.

Talking with Irene later, I asked if she'd ever tried responding to residents by letting them know she understood how frustrating the long waits were and that she sincerely wanted to help but her influence was limited. A few days later I arrived at the Clinic and Irene called me over. She had tried the approach with one resident and announced, 'you know what, it works!' (Field Notes, 2 August, 2010). It didn't correct the problem of long waits or the structures that produced them, nor did it imply a fuller understanding of the resident's life and realities, but it did acknowledge that the limits resided in Clinic structures rather than with the resident or with her and recognized that they were both positioned in larger systems over which they had little control.

## Chapter 8. Encounters with physicians

*Waiting to be called by his physician, the resident tells me . . . he needs to stay quiet and let [physician] do most of the talking. We enter the physician's office and the greeting is loud, boisterous and warm . . . the physician says he needs to look at the chart which cues the resident to be quiet. The resident leans toward me and says 'See, I told you!' We all laugh. (Field Notes, 10 September 2009)*

In this chapter, I examine the colonial dynamics of the encounters between physicians and residents (patients) which took place in physicians' office-exam rooms. These rooms varied in size from one that was large enough to accommodate a resident and two support people to others that barely had room for one support person. The rooms were much like any other clinic, each with an exam table, a few chairs, a countertop, sink and supply cupboard, racks filled with forms, and an assortment of informational posters on the walls.

Outside the DTES, most family physicians were remunerated on a 'fee-for-service' basis which involved billing the BC Ministry of Health for services rendered. This typically resulted in booking patients every 10 minutes to generate sufficient revenue to cover physicians' time and the costs of rent, staff and supplies. In contrast, Native Health physicians were not responsible for operating costs and worked on a 'sessional basis', which involved receiving a flat fee of \$440 for a 3.5-hour 'session'. Sessional funding recognized the increased complexity and acuity of residents' concerns and was reflected in booking appointments every 20 minutes. While twice the amount of time allocated to patients in clinics outside the area, it was still frequently insufficient, with patients' visits often running much longer. One physician said he could easily spend an entire morning addressing some residents' concerns and still feel that he'd barely scratched the surface. Physicians thus had to select which concerns needed immediate attention and which could wait.

My analysis is positioned in the tensions physicians felt between their dual obligations to support and regulate residents. These roles indexed areas where medical knowledge, technologies and practice (and hence, physicians' authority) are relatively secure or are limited, uncertain, and laden with risks. The contrast in physicians' support and regulatory roles is exemplified in HIV care and pain management. The relative

in/security of medicine in addressing in these areas illustrates the different ways that beliefs about Addicts inform physicians' practice. While physicians could see residents as vulnerable with limited capacity for self-care in both roles, beliefs about Addicts' untruthful and disorderly behavior were most evident in the context of physicians' regulatory role and, specifically, in the medical management of pain. The convergence of these roles in caring for individual patients creates an inherent tension in medical practice. As one physician explained 'dealing with the person's addiction and dealing with the person's HIV is sometimes . . . [a matter of] carrots and sticks' (Interview, 3 June 2010). The challenges of physicians' regulatory role in the management of pain are well recognized and findings of my study were largely congruent with existing literature. The emphasis of this chapter then is on examining the colonial dynamics of physicians' support roles to illuminate how these could reproduce residents' experiences of judgement, governance and exploitation. Before I turn to this, it's important to recognize the diversity of physicians' practice. Since my analysis of encounters draws from fieldwork in the Clinic and from my broader, ongoing relationships with residents outside the Clinic, I also highlight some data from my observations of clinical encounters and post-encounter interviews.

### **8.1.1. Physicians' diversity**

*Doctors, like any profession, get lumped together [in the assumption] that we all work in the same ways, and we don't. (Physician, Interview, 23 June 2010)*

When one physician told me, "it requires a very special type of physician to do this work and to do this well", he was expressing sentiments widely shared among providers in the Clinic (Physician Int, April 19, 2010). During interviews physicians told me that those who expected to see rapid changes in behavior or expected residents to follow their advice were quickly frustrated. To practice in the DTES physicians needed to be comfortable treating infectious diseases, mental illnesses, chronic conditions and difficulties that arose from the intersections of poverty, social marginalization and addiction. It required patience, an informal manner, and the ability to accept small changes over time. It was stressful work. As a result all but one physician worked part-time.

Despite commonalities in the nature of practice, the diversity of physicians and medical relationships, presented a significant analytical challenge. Reviewing transcripts of my interviews with five physicians, all of whom I interviewed at least twice, I noticed a recurrent, distinctive theme in how each physician talked about medicine. One focused on 'medical empiricism', another on 'saving lives', the third on 'trauma-oriented practice' and the last two on 'storied medicine' and 'coaching for change'. Physicians' styles of practice, which I saw as expressions of their personhood, influenced how colonial dynamics were enacted in their encounters with residents. Variations were observed in their responses to the industrial temporalities of care, the extent they considered residents' social and emotional concerns and perspectives, and their affinity for relational or conventional ways of relating. An important variation was how physicians understood and enacted their authority. All physicians acknowledged residents' right to accept or decline treatment, but several viewed medical recommendations as the best, correct and/or rational choice. A few physicians acknowledged the limits of medical knowledge and critically reflected on the asymmetries of power. I found these physicians were more open to residents' perspectives and critiques, and considering these in their practice and the development of treatment plans. Physicians also differed in their personal responses to residents' suffering. These responses ranged from a physician who acknowledged being 'somewhat hardened' to the difficulties of residents' lives, to others who talked about the privilege of working with residents.

### **8.1.2. Methodological notes**

In my observation of 49 medical consultations, I only observed overt disagreement, frustration, or conflict in four encounters. As discussed in Chapter 5, the appearance of congeniality was not a reliable indicator of how residents experienced medical care. I conducted 21 post-encounter interviews with 18 residents. Two residents who appeared calm and cooperative during the medical encounter expressed dissatisfaction with the physicians' care. However, I had never met 10 of these residents prior to observing their medical encounter, and a lack of familiarity with me may have created reticence to report negative experiences.

Based on my understanding of residents' communication practices when reviewing detailed field notes of each observation, I identified that in eight (16.3%) of the 49 observations, physicians did not address residents' main concerns, which pertained

to the impending loss of a partner, the stress of being homeless, the fear of death, receiving methadone that day, concern about testosterone, a request for medical marijuana, and pain relief for a medically recognized condition. I conducted post-observation interviews with six residents whose primary concerns had not been addressed. Only two residents expressed significant dissatisfaction with the medical visit. That more residents did not critique physicians when their primary concern remained unaddressed could reflect many things, such as a sense of resignation, fear that I might betray their confidence or that I misunderstood their main concern. However, in my broader fieldwork I found that if residents sensed a provider cared and was sincere in efforts to help them, they were less likely to critique providers for shortcomings in their care.

Seven of the 11 residents with whom I had extensive contact as part of my broader fieldwork reported significant dissatisfaction with their medical care during fieldwork or in our ongoing interactions since then. Over these years, a few residents also temporarily discontinued contact with me for reasons that were similar to why they sometimes discontinued relationships with physicians, such as interpreting a comment as judging, indifferent, or intrusive. The impacts of residents' histories and poverty, and the flux in their social circumstances, stress, and drug use cannot be ignored. I have come to see that misunderstanding and conflict, while part of any relationship, is a more common feature of ongoing relationships with residents. This does not discount the legitimacy of their concerns or experiences, but in my view underscores the instabilities of their lives and how excess exposure to inequity and institutional governance influences their interactions with providers.

## **8.2. Colonial dynamics of physicians' supportive role**

*Anybody in authority – you don't trust or believe anything they say because so many times they break their word. 'Oh yeah, we'll do this for you' and they don't. (Resident, Interview, 22 March 2011)*

In general, colonial dynamics become visible in the inflation or exaggeration of physicians' knowledge, their ability and responsibility to relieve suffering, and the presumed relevance of their care to improving residents' wellbeing. Although most physicians readily distinguished between their support and regulatory roles in interviews, only one physician acknowledged how some supportive practices might be perceived as

regulatory. Mykhalovskiy (2008) found that for many socially marginalized people, 'biomedical knowledge does not act as a benevolent decision-making resource but instead is experienced as a regulatory discourse' which can 'produce resistance' (p. 138). I attribute this to the fact that both roles were structured by the same epistemic, temporal, normative and moral dynamics of colonialism.

### 8.2.1. Talking and telling

*Some of these doctors . . . I find they just rush the people, just like a factory where they [patients] come along a conveyor belt and listen. (Resident, Interview, 18 April 2010)*

Many residents critiqued physicians' tendency to 'talk and tell them how to live their lives'. Although physicians usually inquired about residents' lives, the majority of time in the encounter was spent *obtaining* information for diagnosis and treatment and *giving* information about the condition, treatment and follow-up. Research on the micro-politics of medical encounters (i.e., Waitzkin, 1985, 1991) make it tempting to interpret this as physicians' monopolizing clinic time by asking questions, identifying priorities, and giving information and advice. This was often a component, but the problem of 'talking and telling' was more complex. For example, one physician often asked few questions about residents' lives and there were many extended pauses in his medical visits when neither party spoke. Several residents preferred his approach because they didn't need to second guess the physician's 'real' feelings, and felt he respected their privacy. However, I found other residents, unsettled by his aloof and direct manner, were frequently dissatisfied by his care. Another physician recognized he could 'talk a lot', yet many residents praised his care and support. It seems that the criticism of physicians' 'talking and telling' is less about who occupies the air-time, and more about how physicians' practices and presence reinforce (or mediate) residents' awareness of the asymmetries of power in medical encounters. A factor contributing to the critique of 'talking and telling' is that the translation of a patient's concerns into medical taxonomies draws attention away from the patient to the physician (Barry et al., 2001; Radley et al., 2008). The perceptual impact of this is reflected in residents' distinction between physicians' priorities and their own. The issue of 'talking and telling' did not necessarily mean residents viewed physicians' and their own priorities as oppositional or mutually exclusive, but recognized that physicians' priorities were, in many instances, only *one* component of what made care a positive experience for them. As I discuss in the next

chapter, the problem of 'talking and telling' often reflected the extent to which residents felt their personhood and *being*, not just their bodies, were engaged in the encounter. When medical encounters were focused on the physician's priorities, it left one Indigenous resident feeling 'like a third party in a two-way conversation' (Interview, 13 April 2010). Patients' experiences of invisibility in medical care are not new, nor are they benign. Barry et al (2001) found that medical outcomes were poorest when the patients' 'lifeworld' was ignored or blocked by physicians.

Medical 'talk' could accentuate residents' awareness and experience of the hierarchies in power in several ways. This was often noted by residents in the unquestioned license of physicians to inquire about residents' use of drugs and personal lives. One physician explained to me that inquiries about residents' drug use were part of a complete medical history and informed her plan of care. Such practices were medically justified by realities of the neighbourhood but when residents could not see any relationship between physicians' questions and their own concerns, it was often experienced as intrusive and left them feeling treated like Addicts.

In most visits, physicians inquired about residents' lives and social circumstances, which generated various responses: some welcomed these inquiries and others did not. The appropriateness of such questions tended to be evaluated by residents in terms of the level of rapport in the relationship. One resident explained that physicians had to earn the 'right' to ask questions about his life; his willingness to answer depended on whether a physician had earned his respect. Unsolicited inquiries were often experienced as judgements and intrusions on residents' right to live as they wished. Unless residents invited discussion of their lives, many wanted providers to stick to medical concerns and leave the private matters of their lifestyles alone. 'When they try to cross over, getting into the personal lives', one resident explained, 'that's where the conflict comes in. A lot of the people down here . . . [t]hey don't want anybody to know, like in the professional world, what they're doing' (Interview, 15 April 2011). Although colonial dynamics are generally enacted in the *reductionism* of medical care and its elision of socio-historic contexts, when it came to areas that residents saw as personal and private, many criticized physicians for not being reductionist enough. Although resident's responses to questions about non-medical matters were influenced by the strength of their relationship with the physician, even in well-established relationships their receptiveness to personal questions could fluctuate. Variations between residents

in whether they did (or didn't) welcome inquiries about their lives, and the fluctuations in a residents' experiences over time, presented physicians with the challenge of trying to anticipate their responses with the chance of being criticized either way.

For residents, the problem of medical talk also included the giving of unwanted (and often unsolicited) information, education and advice. The importance of giving patients information about medical conditions and treatment options is encoded in the standards of medical practice (CMA, 2012). For many residents these forms of medical 'talk' reproduced the experience of authorities who professed to know what residents' needed with little awareness of their histories, everyday lives, what it *felt* like to inhabit their realities, and, hence, with little awareness of the frustration or feelings such talk could evoke. I also observed that sometimes when physicians' shared information about the residents' health, such as elevated cholesterol, residents' interpreted it as a directive or judgement, demonstrating residents' sensitivity to the normative assumptions embedded in health care. Even if something like 'high blood pressure' or cholesterol was shared only with the intent of monitoring it over time, it was not difficult for many residents' to connect it to their lifestyles, such as stress levels or diet, and thus as one more thing they were doing 'wrong'.

### ***Time and fear***

Physicians tried to simplify explanations of medical matters and some took pride in their ability to render complex information into terms residents could understand.<sup>53</sup> After talking with many residents about HIV, the basis for some physicians' confidence in this regard was less certain. In my observations of clinical encounters, explanations of HIV invariably included some reference to 'immune systems', 'viruses', 'cells', 'CD4', 'viral load', 'counts', or what one resident referred to as '\$100 words'. Even when physicians thought they were speaking plainly it was still too confusing or complex for many residents. I found that residents who stated they had 'always liked science' grasped information easily. For others the ability to explore medical meanings of HIV to the point of comprehension were not only constrained by terminology but by the temporal dynamics of care. Attentive to physicians' non-verbal signs of stress, many

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<sup>53</sup> On several occasions, when residents told me they didn't understand providers' explanations of HIV, I was unable to resist my conditioning as a nurse and offered unsolicited (and unwanted) explanations. Each time, the residents' eyes quickly glazed over. I subsequently learned to ask before offering such information and every time residents declined my offer.

residents were afraid of taking too much time lest the physician became frustrated or judge them. An Indigenous resident explained:

they won't ask if you understand – they just move along or go in their computer, meanwhile you're sitting there and you're looking at him 'OK, what the fuck did this guy just say?' . . . [Y]ou don't want to ask because you might feel like he's looking at you like [you're] an idiot. So you just agree, smile and nod your head. (Interview, 13 April 2010)

In contrast, another resident credited many years of viral suppression to a physician taking a long, unhurried visit to explain and answer all his questions until he understood. This comment and the quote above imply that if physicians inquired about residents' comprehension the difficulty would be addressed, but it was rarely so simple. Many residents in this study, and more of whom were Indigenous, had been unable to complete more than a few years of school and the limits of their education were an ongoing source of shame. As one Indigenous resident explained, 'I have a very, very hard time asking questions . . . when I ask a question to somebody that's got a lot more education than me – I'm really, really careful how I word things' (Interview, 11 December 2009). This illustrates how the anxieties and fears associated with medical care could preoccupy residents and limit their engagement.

To navigate the risks of asking questions, some residents introduced their concerns as statements. For example, in my field note of one medical visit, the resident began the interaction saying that he didn't think his 'better half is going to last too long. She won't go to the doc' (Field Notes, 28 July 2009). The use of such statements sought to engage the physician's attention without the risk of residents expressing their needs and having the physician dismiss them. In Chapter 5, I mentioned that several residents told me, when providers responded to their requests with the 'no word', it elicited an intense emotional response. For these residents, the reticence to ask questions was both a self-management and a relational-preservation strategy. I found when residents expressed concerns as statements, physicians usually took the hint, but physicians' readiness to engage social and emotional matters varied. As Barry et al. (2001) found, when physicians move beyond the parameters of medicine into social and emotional areas, they are required to draw upon their natural communication and life skills. I observed that when a resident broached such topics with a physician who was less comfortable, adept or ready to engage such concerns, it often left residents' feeling invisible and reinforced their beliefs that the physician was 'just in it for the money'.

Even if residents were comfortable with physicians, the metaphors physicians sometimes used to explain information did not always make sense within the residents' own understandings of the body and illness. For example, to explain HIV, many physicians drew upon military metaphors like the army of the immune system fighting an enemy virus. The metaphor was helpful to many residents but the notion of the body as a battleground confused others. One Indigenous resident, who reported having a holistic understanding of health where balance was central, told me, 'I really don't understand those little army men they talk about . . . for me it's my mind and my heart. Like they're connected' (Interview, 7 April 2010). I took this to mean that understanding wasn't only cognitive but *affective* and *embodied*.

The rapid flow of talk, medical jargon and awareness of time pressures made it difficult for some residents to focus. It created a 'confused feeling' for one resident that often resulted in him 'forgetting' his questions until after he had left the encounter. Another resident told me that medical interactions left her feeling 'dizzy'. Many interactions I observed were between 20 and 30 minutes long. With the pace of information and number of issues discussed in some encounters, I was not surprised that some residents felt confused but by how much they actually remembered. Residents usually attributed the pace of talk to physicians' economic priorities. 'The more [patients] they get through, the richer they get', one Indigenous resident explained, adding, 'that's where all the quick answers come in' (Interview, 15 March, 2011). When I told several residents that physicians were on salary and worked quickly to help as many people as possible, they did not believe me: That physicians would work hard, without any additional financial benefits, was incomprehensible to them. Without this knowledge (or unable to believe it), residents tended to see physicians as motivated by greed rather than the desire to help.

The rapid flow of information in encounters was influenced by industrial temporalities of care and the value of clinical efficiency in medicine (Groopman, 2007; Higashi et al., 2013). Residents' limited understanding of how the temporal and structural context of care contributed to the pace of medical 'talk' also meant they were less able to see how these same factors constrained physicians and sometimes made it difficult for them to focus on the residents' concerns. This was epitomized in one encounter, when the resident's priorities were soon lost in the physician's attempt to address a stream of medical concerns. Before the visit, the resident told me she'd been

called in to start ARVs. She was scared of the side effects and asked me if she was going to die. On entering the office, the physician remarked that the resident seemed nervous. The resident said she was ready to take her meds but was scared about the side effects. The physician said side effects would be discussed when she started ARVs and then quickly moved on to administer a vaccine and address medical matters with a string of terms (CD4, viral loads and other medical conditions), numbers (some up, some down), values (good, bad, doubtful), and implications (referrals, various dates, and return visits). At one point when the resident again asked about side effects, the physician responded that she wasn't starting ARVs that day. When I interviewed the resident after the visit her initial concerns remained unanswered: 'Well, I just wanted to basically know the side effects and when I'm going to die' (Interview, 24 November 2009). Although there are physicians who cope with time pressures by adopting an instrumental approach to care, for other physicians – like this one whose presence conveyed warmth – the constraints on practice, the complexity of medical concerns, and realities of residents' sporadic attendance can become significant obstacles to their ability to remain attentive and responsive to residents' concerns within the visit. In this instance the physician had to juggle time pressures, the administration of a vaccine, complex medical needs (each with their own set of interventions and follow-up actions), the patient's concerns, the partner's concerns, the added stress of being observed by a researcher, with all of this occurring in the small space of an exam room. What surprised me in such instances is not how residents' concerns become overlooked, but how physicians maintained their composure and conveyed care despite the constraints on practice and competing demands for their attention.

### ***Unspeakable questions***

Although physicians often asked residents if they had questions, it was difficult to turn many concerns such as the stress of being homeless, the pain of loneliness or feelings of shame into a medical question. HIV infection brought concerns about mortality to the forefront for many residents, but the spectre of death didn't preclude the ever-present and pressing reality of their drug use. The shame some felt in 'having got themselves' into a situation where they contracted HIV inhibited their ability to ask certain questions. The moral dynamics of health care, which saw the use of illicit drugs as undesirable and made it important for physicians to differentiate between 'enabling' and 'helping' (Drummond, 2012), also rendered some questions that were important to

residents unspeakable. Two questions that a few residents told me they'd like answered were: How did various street-drugs interact with the efficacy of ARVs and impact their immune system? And, how much use of specific drugs could they tolerate without interfering with the efficacy of ARVs or harming their immune system? As one Indigenous resident explained,

I need [the physician] to tell me, 'if you smoke half a ball [of crack] a week, you'll be OK'. . . . I need [her] to tell me what's my borderline, what's my safety limit . . . then I'll listen to her. I will [because] I don't want to die. That's the bottom line. (Interview, 24 November 2009)

This resident felt it was unrealistic for her to stop her use of drugs when taking ARVs and explained that answers to these questions would 'make me feel more safe, more reassured' and help to manage her drug use knowing that going beyond a certain level of drug use would damage her immune system. A number of reasons could explain why researchers might find such questions difficult or unethical to study, but what is important here is how seldom residents' perspectives and concerns are considered and how this omission buttresses the medical management of their lives.

### **8.2.2. Problem-solving focus**

*The bulk of the time is spent reducing people's problems down to bite-sized or peggable problems that you can kind of work on. (Physician, Interview, 10 March 2010)*

Although most physicians in this study made an effort to balance the discussion of medical matters with some levity and 'lighter' inquiries about residents' lives, the colonial dynamics inherent in the problem-solving focus of medicine could still make it difficult for physicians to see residents as complex persons who were *also* active in creating a positive healthcare encounter. Professional socialization conditioned physicians (and other health providers) to respond to patients' comments as problems for medical action, but residents offered information and asked questions for a variety of reasons. Some shared information to 'keep the flow going' during the visit and at other times shared information as a symbolic unmasking and giving of themselves in trust. Physicians often intuited the reason information was shared, but in some instances, it was impossible for physicians to know the difference between information as an attempt at social connection, information as a gift, and information as a problem to be solved, without asking. When information offered as a gift was taken as a medical problem,

several residents told me they felt betrayed: that the evolving impression that their physician cared for them had simply masked their judgement and desire to control their lives. After seeing his physician for two years, one resident recalled:

I decided to open it up, you know. [To let him know] what I was like as a person, being an addict, couldn't stop using, getting abscesses from needles and stuff. And I could just see – doctors are not supposed to be judgemental, but they're still people, right? And I could see when I started opening up about some of this stuff [he said] 'Well, you think you should get some help for that?' . . . [H]e thought there was something wrong with me; [that] I should seek help. (Interview, 21 April 2011)

Many residents were reluctant to share information because, as one told me: 'they'll play on it – they'll start getting into "maybe you should do this, maybe you should go see this person, like counsellors . . . and some kind of group". . . . They'll take all that information and use it against you . . . start ordering you around (Interview, 9 December 2009). A related problem reported by numerous residents was that truthful disclosures about their lives or activities, particularly with the use of prescription drugs, were often not believed or met with immediate sanctions or increased regulation. Residents referred to this as 'being punished for telling the truth'.

Residents' responses to the problem-solving focus of medicine not only raised questions of who defined their problems, but also challenged the norms on which the medical definitions of problems were based. Even when residents viewed their use of drugs as problematic, they didn't necessarily see it as The Problem. As one resident explained, 'To most doctors, drugs are the problem – they assume it and that's their biggest mistake. Drugs are not the problem – it's the other issues that people have and are not willing to deal with' (Interview, 21 April 2011).

In Clinic observations, physicians often asked how residents were doing 'drug-wise' and affirmed residents' efforts to reduce their use. There was only one interaction where the physician broached drug and alcohol counselling without the resident initiating the topic. When I asked physicians how they understood addiction, several said that the main source of their knowledge about addiction had come from their interactions with residents. Of note, none of the physicians used the definition in the medical addictions literature which defines addiction as a chronic relapsing disease of the brain (Wood et al., 2013), However, all physicians saw residents' use of drugs as fundamental to their

health concerns and viewed the reduction of drug use as a laudable objective and an indicator of movement toward improved health. A few residents who had stopped drinking and using drugs took pride in their sobriety and reiterated the harms of drug use. Other residents found that cleaning up introduced a host of *new* problems: loneliness, boredom, anxiety and depression, as thoughts of their past, once held at bay by drug use, now preoccupied them. If cleaning up meant feeling down, the ‘problem’ of addiction was less clear.

### **8.2.3. Morality: ‘I know better’ vs ‘I know my body’**

Residents often expressed their resistance to the abstract nature of biomedical knowledge by declaring ‘I know my body’. No matter how much knowledge or power providers had over their lives, the irreducible fact of residents’ bodily experience would always remain beyond providers’ grasp. I saw the statement as a plea for physicians to recognize the limits of their knowledge and to accept that residents’ knowledge was also empirical and experientially valid. Many residents, like patients in other studies, evaluated the veracity of medical information through their social networks, experiences and bodily responses to treatment (Balshem, 1993; Mogensen, 2005; Roberson, 1992). Two residents, unsure whether to believe medical explanations of HIV, told me they stopped taking ARVs to see what would happen. Information they had received from their physicians was confirmed when they started to lose weight and their blood tests showed the progression of HIV. Another resident, given medication to discourage alcohol use by making someone ill when drinking, found she could still tolerate weekend alcohol binges while taking the medication. What physicians and other providers might view as a ‘risk’, a resident might see as an advantage. For example, residents were told not to drink alcohol when taking opiate medication as it could intensify the side effect of sedation and reduce breathing which increased the chance of aspiration and suffocation if they vomited. One Indigenous resident was exasperated by such cautions: ‘How many times do they have to tell me not to take T3s with alcohol! Sometimes it works better when you drink! (Field Notes, 3 March 2010). In other words, the point of taking a T3 was to reduce pain, and the analgesic effects were heightened when taken with alcohol. It was also difficult to take providers’ concerns about increased sedation seriously since the regular use of street-drugs and alcohol frequently altered residents’ consciousness and, in their experience, usually had no apparent or immediate ill- effects.

'I know my body' was a rejection of medical dominion over residents' lives and bodies and exposed a contradiction: biomedicine values empiricism yet residents were expected to accept medical knowledge as an article of faith. It was difficult for residents to have unquestioned confidence in authorities when they felt authorities were primarily concerned with controlling their lives and using their bodies for profit. With many who had professed 'care' in the past and let them down, the one thing residents could rely on was their own experience. When the default setting was mistrust, bodily experience often confirmed the truth of medicine and physicians' care in a way no amount of science, talking or telling ever could. In their vigilance to identify those who tried to manipulate, harm, or exploit them, physicians' efforts to influence residents' decisions were just as likely to increase their resistance.

#### **8.2.4. Change and choice**

*I tell them out in the street, don't let them push you. It's your time, it's up to you. (Resident, Interview, 20 December 2010)*

The core activities of medicine include trying to prevent, ameliorate and alleviate suffering (CMA, 2004). Physicians' ability to fulfill these aims often depends on patients' reports and their compliance with treatment plans. It is thus not surprising that the residents most likely to enlist physicians' trust were those perceived as sincere and motivated to change. As one physician explained, 'If someone says something and actually acts upon it, I usually tend to support those people very far – those are the people I feel quite good putting extra effort into' (Interview, 24 February 2010).

It was more difficult for physicians to interact with residents they saw as able but unwilling to change. As one physician explained: 'The folks who are not really wanting to do what I think is the right thing for them to do with their health, I am a bit more frustrated with and have less time for' (Interview, 19 April 2010). Others have found that physicians' sense of effectiveness is tied to being able to connect their practice to evidence of improved health (Balshem, 1993; Epstein, 2017; Groopman, 2007; Hilfiker, 1994). This helps explain the prominence of HIV care in this setting as it was one obvious area that physicians' could realize their healing aims. However, with the suffering of residents' lives so visible and with the demand for care so often exceeding the availability, physicians also wanted to know their time and skills were used to best advantage.

Most residents I met were not opposed to change: many desperately wanted to get off drugs, move out of the area and have a 'normal life' but the exigencies of their lives clouded the path between 'here' and 'there'. Physicians recognized that many factors worked against change and how even small changes could take many years. It was only as fieldwork progressed that I started to realize that health services overlooked how residents' histories and realities created a *way of being* that reflected a social and moral world characterized by the ever present threat of rupture, failure, shame, and fear – which was outside most providers experience but had a significant bearing on the possibilities for change. Having faced struggles similar to those of residents, an Indigenous provider reflected this, telling me: 'You have to have experienced these things in order to help people effectively; they're not things a person who grows up in a loving family, with enough money, someone who's middle-class, can understand' (Field Notes, 19 August 2009). Many residents wanted to forget the past and were reluctant to share anything that might compromise physicians' positive regard. Through relationships with physicians (or other providers) some were able to imagine a hopeful future, but the gritty, uncertain terrain of residents' lives and its distance from the terrain inhabited by providers' therapeutic aims and futures, remained unrecognized. I glimpsed this distance on a long walk with a resident one day. The ease between us led to an unexpected opening to discuss his past, as he started recounting stories of his involvement in violent crime, recalling (and reliving) the thrill and feeling of power. I struggled to reconcile the stories, images and emotions they evoked in me with this person I had come to know and like. When I later shared my reaction, he was disturbed and said what I and other health providers missed seeing was:

I was innocent at one time. The only way to survive was to put on masks. Drugs were something to hide behind because you didn't want people to know that you're weak. . . . So I put on masks so people wouldn't know who I was. . . . Health people say 'we all have choices'. No, you don't: sometimes the only choice you have is between something that's wrong and something that's worse. (Interview, 4 May, 2012)

The opening into his life exposed the distance between the middle-class social and moral assumptions, on which health care and its therapeutic aims were often built, and the uncertain social and moral worlds of residents' lives. It also helped me see the internal moral conflict that some residents grappled with in their yearning to be known and accepted while knowing that the very disclosures that make this possible could

evoke providers' judgement. In examining the stories of people who have experienced various forms of social extremity, Kleinman (2006) observed that moral experience – as in what comes to matter to people and to societies in specific contexts– “could be far from good, even malign” (p. 2). As Maracle (2015), referred to in Chapter 2, elaborates, in a social order founded on colonialism, the violence enacted through societal understandings of moral experience shapes the everyday lives of those positioned lower in social hierarchies who directly experience these impacts in the uncertainties of everyday life. The realities of residents' lives can call into question the middle-class assumptions which imbue notions of individual choice and their ability to embrace and attain desired futures. In other words, the resident's comment to me about moments in his life where there is no desirable option, attest to the differences between the moral terrain of residents' lives and those of most providers, and what kinds of choices and changes become possible within these. How does one connect the dots between the disparate worlds of residents' histories, the familiarity cultivated in everyday encounters, and the moral aims of care? As Kleinman (2006) argues, simplistic moral distinctions of good / bad, which I extend to the moral foundations of health care, may offer ‘no help and may even get us into deeper trouble’ (p. 233). This does not preclude the possibility for residents to change, but recognizes the hubris of providers' aims and efforts to influence. Reiterating the plea of a resident quoted in Chapter 6 for providers to just ‘let residents' be’, one Indigenous resident explained:

the people down here have seen and done a lot of things that the staff and the health care workers don't understand. Like I've seen a lot of my friends die in front of my face, I've seen a lot of my family die in front of my face. And there's going to be a lot of pain with people down here and sometimes [providers] don't see that or understand that. (Interview, 13 November, 2010)

The inference was that *if* providers knew ‘what it was like’, they would see the limitations of their knowledge and be less inclined to judge and try to change residents. It was not, as some providers believed, that residents didn't value their health; the fact they endured the inconveniences and risks associated with accessing health care was evidence that they did. Most residents realized the importance of health care but wanted it on their terms – to get it when they were ready and to get what they needed without the unwanted moral and regulatory trappings. This too was a moral position, but was often incompatible with the structures, norms, and moralities that informed medical practice.

### ***Choice, control and perplexity***

All physicians talked about the importance of respecting residents' choices and being non-paternalistic, but when the pursuit of therapeutic goals did not consider residents' perspectives, physicians' practices could easily be experienced as forms of coercion and control. Many residents reacted to such practices and expressed it in response to physicians' method of dispensing ARVs. One resident recalled:

When I went back to reload [with ARVs], they only give me a week and I was like, 'what, you only give me a week?!' 'Well', he said, 'how are we supposed to keep track whether you're taking them or not?' I said 'Excuse me?!' He said, 'Well we don't know if you're actually taking them so this way we can make sure that you're actually taking the one's we give you.' 'OH!', I said, 'who are you to make that decision?! Who are you to even make that *assumption*?! I don't even have to deal with you. . . . You know *I choose* to come here!' (Interview, 23 December 2009)

In my observations of clinical interactions, residents had the most input into decisions about whether to increase or decrease their dose of methadone, the interval for ARV pick-up, and the choice of pharmacy. Physicians asked or confirmed residents' preferences for various pharmacies but in some cases restricted their choice to a list of 'approved pharmacies'. This list included pharmacies with reputable dispensing practices and excluded those known to have unreliable, unsafe and (to some physicians), unethical practices (Matas, 2017, March 27). Dispensing daily medications was lucrative<sup>54</sup> and pharmacies known to give residents financial incentives to enlist their prescription business were excluded from the list. Using pharmacies on the approved list was not a concern for many residents but others objected as it denied them access to a legitimate source of income. That providers' might accuse residents for participating in initiatives 'for the money' implied that concern for their well-being and financial need were mutually exclusive and underscored the moral prerogatives of affluence. 'If you're not in need', one resident said with irritation, 'suddenly you have an opinion of [residents], but me, I'll take whatever you give me' (Interview, 9 February, 2009). Although a few residents had told me that their physicians were more flexible in supporting their choice of pharmacies when I was not there, only one physician told me that he did not restrict residents' choice of pharmacies. In his view, it was the College of

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<sup>54</sup> During fieldwork, the BCMOH paid pharmacies \$8.60 to dispense a medication daily (T. Tam, personal communication, August 8, 2009). Many residents received multiple medications on a daily dispensed basis.

Pharmacists' role to regulate pharmacies and if local pharmacies were licensed to practice, then residents had a right to access them. Given the dubious practices of such pharmacies, it meant the physician lived with a greater level of risk for harm to his patients and/or third parties. By recognizing it was the College of Pharmacists' role to regulate pharmacies and not his, the physician did not deploy the power vested in medicine to overrule and morally filter residents' preferences.<sup>55</sup>

Another practice was withholding prescriptions for methadone, pain medications or ARVs until residents had completed their HIV blood work. Physicians regularly monitored HIV blood work. If a resident was taking their ARVs and the results of bloodwork indicated a progression of HIV infection, it could mean they had developed a resistant strain of HIV which required further investigation. This had implications for their health so it was important for physicians to know this before issuing another prescription. Withholding a prescription until bloodwork was completed was often a last resort when reminders failed to have effect. In such instances it could seem like residents' were not taking responsibility for their health and/or that they might need a more structured 'reminder'. For many residents, such practices epitomized the manipulative and infantilizing tendencies of providers. As one Indigenous resident told me: 'I needed my pills one day and [physician] wouldn't give them to me until I got my blood work done. . . . I said if that's the way you're going to play it, shove it up my ass and [I] walked out' (Interview, April 4, 2011). Another resident explained this practice: 'it's led me to the point of almost violence with them: *absolutely flipping!*' (Interview, 7 June 2010).

With the exception of their regulatory role, physicians talked about the importance of not being paternalistic, but when it came to practices that sought to support therapeutic aims, like those described above, they were less likely to see these as paternal but as ethical duties that were part of physicians' professional responsibilities and practice. As one physician told me 'I don't take chances with patients' lives' and although some residents accused her of being paternalistic she explained such actions were 'not to punish patients' but to know whether medications were effective (Interview, 22 June 2010). Delivering pain medications to patients' homes, she had witnessed other

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<sup>55</sup> Sometimes physicians curtailed residents' choice of pharmacies by assuming that it would be convenient for residents to fill prescriptions of methadone and ARVs at one pharmacy. Since the provincial Drug Treatment Program only released ARVs to pharmacies with reputable dispensing practices, this practice denied residents the option of having methadone dispensed by pharmacies offering financial incentives.

residents lining up outside apartment doors waiting to purchase patients' pain medications and saw how difficult it was for patients to resist this. The example highlighted the ethical messiness of colonial dynamics in medical practice. In such instances, the actions needed to sustain therapeutic outcomes and fulfill one's professional duties seem to foreclose possibilities for residents' self-determination. Simpson (2017) argues that bodily sovereignty should be treated with the same urgency as political sovereignty, but what does that mean when respect for self-determination has the potential to harm oneself or others and when the exercise of self-determination exists within a structured asymmetry of power? How is 'harm' defined and who decides? Physicians are responsible for preventing harm and promoting therapeutic outcomes, but how far do these responsibilities extend since it is impossible for any provider to fully know, let alone to manage, the specific social contexts of residents' lives. What happens when the ethics of care and patients' right to self-determination collide? The prioritization of self-determination in such instances still leaves residents in pain with a strong likelihood they will return to physicians for pain relief. It returns me to the uneasy question of earlier chapters: Do residents' have accountabilities to physicians (or other providers) when receiving care?

### ***Pathology and desire***

Physicians are ethically obligated to provide information to help patients make 'informed decisions' about their medical care, to make 'every reasonable effort' to communicate in a way that the information is understood, and to respect the right of a 'competent patient' to accept or reject medical care (CMA, 2004). But what counts as 'enough information', 'reasonable effort' and a 'competent patient' is subject to physicians' assessment (Lee & Lin, 2010). The readiness to accept residents' right to decline treatment varies with the stakes. When the stakes have significant implications for residents' physical health, such as declining ARVs, accepting a resident's decision as informed was, for most physicians, contingent on feeling that they had given 'all the information' and 'done all they could'.<sup>56</sup> By the time physicians had 'given all the

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<sup>56</sup> Fainzang (2002) found physicians sometimes withheld information and or exaggerated risk to promote therapeutic goals. During fieldwork, a study in Switzerland had found no cases of sero-conversion among monogamous sero-discordant couples (where one person is HIV positive and the other HIV negative) when the HIV-infected partners' viral load remained undetectable (Vernazza et al, 2008). The 'Swiss Statement', as it became known, declared that monogamous, sero-discordant couples no longer needed to use condoms. At an HIV in-service for health

information' and were able to accept residents' decisions, residents often felt harassed and angry. Some residents found it easier to submit, later stashing or throwing out their medications.

For physicians, accepting residents' decisions to decline treatment was not always a simple matter of accepting 'no'. With one resident, I observed that when it came to missing appointments, not completing investigations or follow-up, she often claimed, 'no one told me'. It was always possible that she not been informed or had forgotten, but given her recall of other matters it was also possible that it was a strategy to reduce embarrassment, deflect criticism or responsibility for her actions. When it came to ARVs, no provider was willing to chance if residents had or hadn't been given enough information. In this case, respecting residents' right to refuse ARVs meant respecting their right to a protracted, painful, and *preventable* death. With HIV care, residents tended to be seen as choosing between the rationality of medical treatment, with its promised extension of life and improved physical health, and the irrationality of declining treatment with the likelihood of a foreshortened, painful life. Some residents felt that their dependence on physicians and need to maintain their goodwill hampered their ability to refuse treatment. Others stated their concerns and perspectives but physicians (and other providers) didn't listen. As one Indigenous resident told me, 'I will tell you what I think, but I won't say it in a way that will hurt you, so you have to listen very carefully' (Interview, 29 May, 2010). Others told me they repeatedly declined treatment but physicians (like providers outside the Clinic) didn't listen or tried to 'talk them out of it'. The struggle to be heard was exemplified in one Clinic observation where the Indigenous resident, 'Jeff', repeatedly refused treatment for hepatitis C virus (HCV). While the physician's behaviors were not typical of the visits I observed. I include this example because it illustrates how the medicalization of residents' lives can discount legitimate – *rational* – reasons for declining treatment that are external to a medical framework.

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professionals in Vancouver, a prominent medical researcher at the BC-CfE expressed concern about findings of the Swiss study 'getting out' to people in the DTES. I did not explore whether or how physicians shared this information as my Clinic fieldwork was complete by this time, but numerous residents' told me that sexuality was rarely discussed by physicians and then, primarily in the need to 'use protection' which reinforced the pathologization of their sexuality, and associated feelings of shame. While some residents felt physicians had no business enquiring about their sexuality, others had much to say about the emotional and social impacts of HIV for their sexuality, relationships, desires for intimacy and understanding of their bodies.

The visit began with the physician, 'Dr. West', asking if Jeff had followed up with plans to attend an HCV support group, which had been discussed in the last visit. I recorded the interaction in the following field note:

Dr. West asks, 'Did you go?' Jeff laughs and says, '*NO!* Cause I'm still drinking, and I need something to replace it before I'm able to quit!' After some discussion, Jeff says he can quit if he has to, 'but I don't want to!' The doctor makes another pitch for treatment. A loud groan ushers from Jeff: 'You're just wasting my time – what am I [doing] going to meetings – I want to be out making money!' He could skip the meetings, Dr. West says; the treatment involves one injection a week. Would he like more information? In a loud voice: '*I don't want more information! I want [this visit] to be quick!*' (Field Notes, 10 January 2010)

Always joking, whether intoxicated or not, Jeff avoided all serious discussions with providers (and researchers). The only way to engage this resident was on his terms. Most days were organized around collecting bottles and using the money to buy beer, which he enjoyed in the privacy of his apartment that evening. As I came to know Jeff, I realized that alcohol was not just a source of pleasure and relaxation – it structured and gave purpose to his days. The problem in addressing Jeff's health was not his so-called indifference to his health but the limited medical view of well-being. As understood by Jeff, well-being was less about longevity than the quality of life while living it. I later learned that Dr. West was involved with an HCV study. While this enabled him to offer Jeff a very expensive treatment with significant, potential health benefits for his health at no cost, the conflation of research and practice lent complexity to Dr. West interests and, perhaps, contributed to the difficulty he had in accepting Jeff's decision.

### **8.3. Conclusion**

This chapter examined how colonial dynamics were enacted in medical care, where the asymmetries of power privilege the perspectives, priorities and understandings of physicians. Physicians' personhood is reflected in styles of practice which reflect different understandings of medicine, medical authority and medical relationships.

The delivery of medical care presents risks and challenges for providers and residents' alike. General experiences of the other make it difficult for both parties to cultivate trust and respond to the other as a person. I have demonstrated how the

colonial dynamics of care enacted in physicians' support role can render the socio-historic context and multiplicity of meanings associated with residents' health concerns invisible. While residents and providers both talk about the importance of respecting residents' self-determination, I have illustrated how this becomes more complicated in practice. While physicians' support roles are often experienced as regulatory, there are also many times when medical relationships are experienced as sources of support and affirmation, which I address in the next and final chapter.

## Chapter 9. Conclusion

*You can just tell by their attitude if they're a good doctor or not – by the way they treat you, the way they talk to you, the way they approach you, their tone of voice, the things they say to you. (Resident, Interview, 27 August 2009)*

In this dissertation, I have examined how colonialism is enacted in an inner-city health agency where the asymmetries of health care relationships are intensified by marked differences between the social and material realities of residents who live with HIV and use illicit drugs and health care providers. By tracing how colonial beliefs about Europeans' 'civilization' and Indigenous Peoples' 'Savagery' are mirrored in beliefs about the Professional and the Addict, I have demonstrated how processes entailed in the colonialization of lands continue to be enacted at the level of bodies. Just as beliefs about Savages justified colonial dispossession, governance, and inequities in the acquisition of wealth, beliefs about Addicts elide the personhood of residents and justify the professional governance of lives while detracting attention from the political and economic investments in 'care' and the social conditions that create their suffering.

Colonialism is the context of life in Canada and, more specifically, in the DTES and in health encounters. Although there are important differences in the impacts of colonialism for Indigenous and settler residents, both share everyday experiences of social and economic marginalization and exposure to institutional governance. On this basis I have argued that critiques of colonialism are relevant to understanding the experiences of all impoverished residents in the DTES. I conceptualized the ongoing processes of colonialism as 'colonial dynamics': a term I introduced to examine the interacting hierarchies of power which constitute colonialism and influence provider-patient interactions. I discussed, for example, that providers' knowledge and time were taken as more important than residents' and that the presumed moral good of health care often superseded residents' priorities and perspectives. Focusing on colonial dynamics allows an analysis of the processes, discourses and structures that shape health care relationships separate from the impacts of colonialism that are visible in social, material and political inequities and embodied in health inequities.

Residents' experiences of health care attest to the ongoing impacts of colonial dynamics and can be grouped in three critiques. The complaint that 'they treat you like an Addict' expresses residents' experiences of discrimination, judgement, infantilization and being treated like a number. The second critique, 'they try to control you', indexes residents' experiences of governance, coercion, intrusions of their privacy, and disregard for their right to self-determine. And finally, 'they're just in it for the money' reflects residents' awareness of their bodies' economic value and the fact that providers derive professional and economic capital from care irrespective of how residents' experience it. Although I have examined these critiques in the context of health services, they also characterize residents' broader experiences with systems of authority. In contrast to providers' beliefs about the vulnerability and danger of Addicts, residents defined themselves by their strength and resourcefulness, a view that recognizes the fortitude entailed in being able to survive in the DTES.

In the highly structured setting of the Clinic, the industrial temporalities of care emphasized efficiency and sustained the flow of patients through the Clinic. In the Clinic reception area, discussed in Chapter 7, the number of residents seeking help was brought into alignment with the supply of medical services by a filtering process that was structured by the availability of medical appointments and need to maintain a safe and orderly environment. In medical interactions in physicians' office-exam rooms, discussed in Chapter 8, I argued that the distinction physicians made between their supportive and regulatory roles indexed the relative efficacy of medical knowledge and technologies in addressing various health concerns. I explained that, regardless of how physicians differentiated their roles, residents often experienced physicians' supportive practices as regulatory and judgemental. Providers rarely saw how the moral and governmental nature of their support practices could elicit residents' frustration, cause them to withhold information or alienate them from care. Residents' critiques and efforts to navigate these through health work, when expressed or noticed by providers, were likely to be attributed to the unreliable or untruthful behaviors of Addicts rather than to the ways that colonial dynamics are enacted in providers' practice. Across the Clinic, when residents' behaviors or needs were seen to potentially disrupt the flow of patients or touched areas where providers' knowledge and authority was vulnerable, stereotypes of the Addict were more apparent and legitimized providers' enactment of discipline. I elaborated how

beliefs about Addicts were also produced by the influence of colonial dynamics in the broader context of health services and Clinic structures.

## 9.1. Something more: Moral violence

Residents' critiques indexed the cumulative affective and spiritual impacts of colonial dynamics and inequities on *being*. One resident who had stopped using drugs and had left the area described life in the DTES as a process of institutionalization: 'I'd been down there a long time [and] for me that bitterness grew – a bitterness toward myself that I couldn't drag myself from standing in lineups' (Interview, 3 January 2011). The excess of services and shelters in the DTES enabled numerous residents to live for years without having to spend money on food, clothing or shelter. As one resident explained, 'Everything is supplied for you as long as you're willing to stand in a line-up. . . . Why would I buy food when I can get it for free? Why waste money on it? I don't have to do that, so I can spend the rest of my days chasing dope' (Interview, 3 January 2011).

But these free services came at a cost; one resident who stopped using drugs found that his dependence services had 'robbed' him of the ability to shop and make decisions.<sup>57</sup> When I asked one Indigenous resident about this, he explained: 'they just lose their will power . . . their inner strength . . . and a sort of hurt depressed feeling gets in[to] them' (Interview, 13 April 2010). He then shared how, at times, he had wondered if the contempt he felt from providers reflected a fundamental flaw in himself:

A lot of [providers] they'd sit there and look at you like . . . they were trying to put me down [like I was the] lowly lowest level of human that could be. . . . You kind of think about that, [you start wondering] maybe they're right? Maybe they see something [in me] that I don't know about. Maybe they see that I should be out here on the street and [maybe] I'm supposed to be out here? And [then] I was thinking, 'nah, they can't be right either'. So I'd argue with myself on the inside (Interview, 5 February 2010).

When I shared such comments with another resident he told me, 'there's way more to it than just everybody hating me [as an explanation of] why my life sucks. It's not because

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<sup>57</sup> Some providers used the term 'disempowerment' to describe the deleterious impacts of the service industry for residents. Although residents' agency was often 'disabled' in their interactions with providers (Illich, 1977), agency and resourcefulness were required to survive in the DTES.

everyone hates me, it's because / hate me' (Interview, 13 April, 2010). Reflecting on his experience of being homeless for several years, a different resident found:

You start not to care what society thinks of you. . . . You become cold and unfeeling because nobody's helping you, because nobody's there for you anymore. You withdraw from the working class of society, the family class . . . you don't care about the dreams you used to have or the things that you used to like. It all becomes a straightforward focus: What can I get from anybody? What can I take from anybody? That's all there is to it. (Interview, 30 December 2011)

Standing in one line-up after another, day after day for several years, one resident explained, 'the prevailing attitude [becomes] that we deserve this' (Interview, 3 January 2011). While providers' work was socially recognized and compensated in wages, residents' work to survive and the impacts of the routinized indifference of services were invisible. Since residents were unable to influence the way services were offered, seeing services as entitlements rejected the notion of services as acts of benevolence and instead made the work of survival visible as prerogative of citizenship. I saw these 'entitlements' as gestures of resistance to the dehumanizing impacts and injustice of inequities.

Accessing care for a number of male residents was an experience of emasculation. 'What men need', one Indigenous male resident told me, 'is identity. . . . [Here] they're just sheep and cattle being shuffled along.' (Interview, 17 April 2011). Given the importance male residents attached to independence, not showing weakness, and 'standing one's ground', discussed in Chapter 7, I then asked how he 'stood his ground as a man' when accessing services. He replied, 'it's impossible; you can't. They [providers] knocked the legs out from me time and time again until I just gave up. These little instances, it's nothing that you can really add up and make a complaint about because it's such a slow eating-away at your personality' (Interview, 17 April 2011).<sup>58</sup> The wounds to residents 'being' show that the banality of colonialism, like the banality of evil – a term coined by Arendt (1955/1968) in relation to a Nazi criminal who said he was just following orders – often made the micro-practices entailed in the colonial assault on residents' dignity and personhood difficult to name. These findings attest to the collective, affective impacts of colonialism on residents' personhood and being. In

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<sup>58</sup> The erosion of 'self' among socially marginalized people through sustained exposure to discrimination and inequity was also documented by Desjarlais (2000).

previous chapters I also documented the affective impacts for many residents in the fears and risks of interacting with providers, in the feelings of despair, the erosion of hope and ability to self-determine. On this basis, I have argued that in health care, the affective impacts of colonial dynamics, which include normative violence (Million, 2013), also enact moral violence against residents. However, residents' responses to living in the DTES were not static, singular or unitary. Some residents talked about the rising violence and the growing governance of their lives, but they also had a sense of community and no desire to leave.

## 9.2. More still: The power of personhood

Despite the prominence of critiques in residents' general experiences of health care, I observed that many also had close supportive relationships with specific providers. These health care alliances demonstrate the generative power of personhood to temporarily ameliorate residents' experiences of colonial dynamics and were important sources of stability and support in many residents' lives. Alliances were also important sources of personal and professional satisfaction for providers. As discussed in Chapter 2, I understand personhood as the *recognition of* 'the other' as a complex, unique person (rather than a member of a category), as the *expression* of everything that makes one an individual, and as the basis of social life. Personhood is entangled with colonial dynamics and can thus be expressed in ways that intensify and mediate residents' experiences of inequity and in behaviors that are contradictory and incomprehensible, even to others and the individual themselves. In this study I concentrated on discussing how residents' personhood was expressed in their critiques, the strategies they used to survive the uncertainties of street life and in their health work. And, how providers' personhood was expressed in their individual styles of practice, discussed in Chapter 8, and in the ways that feeling accepted as persons in the workplace influenced the delivery of care more broadly, discussed in Chapter 7.

While the diversity of providers' practices and health care relationships preclude generalized or unitary notions of 'best practice', I found a number of attributes and practices contributed to the formation and maintenance of many health care alliances. With a few residents, I observed that when a provider consistently responded with an open, accepting manner and positive regard, residents began to attribute positive intent

to situations where the providers' actions were unclear rather than impute their conditioned tendency to see such instances as providers' attempts to judge, control, and exploit them. As the following example demonstrates, this shift was often subtle but, given many residents' suspicion, I saw the change as significant.

One physician, 'Dr. Rivers', was notable for the way his practices helped establish alliances. For example, one Indigenous resident, 'Amy', told me several times how she resented providers talking about her behind her back. I had witnessed her frustration and sense of betrayal when she learned that information she had shared in confidence with a provider in the Drop-in Centre had been shared with other staff and led them to contact support workers in the apartment where she lived. Numerous residents had told me their physician was the only person they could trust. In this respect, Amy's trust in Dr. Rivers to respect her confidentiality was not unique but observing one of her medical visits I gained new insights how a consistent experience of unconditional positive regard could influence residents' responses. During her medical visit, Dr. Rivers mentioned he had been talking with a provider at the Drop-in Centre who had told him about her plan to train as a chef. Following a brief exchange about this, the visit then moved on to medical matters, which included the resident stating she wanted to switch from receiving her ARVs at the Drop-in Centre to getting them from a nearby pharmacy. Dr. Rivers affirmed her decision without question, made the arrangements, and then brought the visit to a close. Afterward, in our post-observation interview, when I commented that Dr. Rivers hadn't asked why she wanted to switch her medications, Amy responded, 'I think he knew.' In my field notes after the interview, I wrote:

Later in the interview she shares being surprised that Dr. Rivers mentioned she was trying to get into a cooking course. I ask how she felt about this given how private she is and how annoyed she became when other providers had communicated about her without her knowledge. With the cooking course, she surmised Dr. Rivers was asking the provider in [the Drop-in Centre] how she was doing 'because he doesn't see me much' (Field Notes, Post-Encounter Interview, 3 November 2009).

Dr. Rivers did not know the rationale for her request to transfer medications to the pharmacy, nor had he explained why he was talking to the provider from the Drop-in Centre about her. Amy imputed positive intent to both moments of ambiguity – *assuming* Dr. Rivers understood why she wanted to transfer her medications and *assuming* the inquiry about her life was motivated by his concern for her. Positive attributions were not

only conditioned by relationships over time but were also conditioned within the clinical encounter. In addition to Dr. Rivers' acceptance of her request to transfer her ARVs to a pharmacy without question, there were several instances in the same encounter where he prefaced his responses with an affirmation of her desires and statements. For example, when Amy told him she had quit drinking he didn't ask questions, such as when or why, but said that he had 'learned she has terrific will power once she sets her mind to something' (Field Notes, 3 November 2009). He also communicated empathy non-verbally. As he was recommending a medication to reduce itching I noted: 'Amy is rubbing her neck where the skin gets itchy when she doesn't take this medication. Dr. Rivers is rubbing his neck sympathetically as they talk' (Field Notes, 3 November 2009).

A shift in conditioned expectations of poor treatment was also observed with other residents. When one male Indigenous resident changed physicians, his aversion to health care and characteristic ambivalence toward providers, which had featured in every interaction with me over a year, gradually subsided. Evidence of the 'positive turn' in this instance was observed in the marked *absence* of his ambivalence and complaint. When I asked another Indigenous resident, identified as 'difficult' by several providers, how his close and supportive relationship with Dr. Rivers had developed he replied: 'He took me seriously, didn't lump me as a drug addict. He talked to me on a level playing field.' As he started to realize Dr. Rivers was interested in him as a person, the resident told me that he started to listen to what the physician was saying and started to take an interest in his health and 'not just go through the motions. He cares so I care, I care so he cares. When he sees that I'm caring, he gets a charge and I get better care. It's a synergy' (Interview, 5 November 2009).

As argued in previous chapters, when residents feel recognized as a person, they were more able to recognize the provider as a person trying to help, rather than as another authority judging or trying to control them. As this quote shows, it could also impact their health behavior. When one recognized the other as a complex person, it produced a space for each to exist more fully as people. When this didn't happen, for example, when providers responded to residents with indifference, frustration, or a manner of authority, residents often became defensive and tension quickly escalated, the resident withdrew and/or assumed a passive manner. This power of recognizing each other's personhood infused interactions with vitality – humour, stories, affection – and built residents' trust in and respect for the provider. The power of personhood, as

mentioned in Chapter 2, is not dependent on a formal education or role and, thus, seems to exceed the parameters and 'power' of scientific medicine. As one physician told me: 'Sometimes it takes many years for people to make the right change . . . and eventually amazing things happen, extraordinary sometimes – things you would not expect a patient can do with their life – it's just amazing!' (Interview, 19 April 2010). Although the physician's belief about the 'right' change or of change as the 'right' aim is open to question, the comment recognizes that people can act in ways that exceed the projections of experts.

The significance of the relationships with Dr. Rivers as I observed and as described by the residents involved, bears similarities to what Simpson (2017) refers to as reciprocal recognition in seeing another's light:

Reciprocal recognition, the act of making it a practice to see another's light and reflect that light back to them, forms the basis of positive identity, self-worth, and dignity in the other being. This in turn, creates strong individuals and strong families, the building block of Nishnaabeg political systems' (p. 184).

Although Simpson describes this in the context of relationships between Native people, I see it relevant to health care relationships in understanding how a deep regard for another's light, builds connections that both counter and have the potential, in time, to erode colonial shame.<sup>59</sup> Saying that, it is important to note, many residents described having an immediate embodied 'vibe' of a providers presents, but *reciprocal* recognition – in terms of being able to recognize the provider as a person - often followed the provider acknowledging the residents' personhood first. Regardless, recognition of personhood doesn't escape the context of colonialism nor preclude providers' expectations for change but it underscores the complexities and potential of personhood and encounters between persons.

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<sup>59</sup> Narrative medicine, developed in the 1990s by physician Rita Charon (2006), argued that taking time to listen and understand patients' stories both humanizes and increases the efficacy of care. Physician Victoria Sweet (2013), who coined the term 'slow medicine', extends this in an approach that draws on premodern medicine to discern the forces inhibiting the flow of patients' 'life force'. Sweet found that when she took *more* time to become familiar with patients and understand their concerns, she intervened less and patients did better.

### 9.3. Building an alliance

Several physicians told me that relationships were a precondition for care: 'You don't have any influence', one physician explained, '[with] somebody that doesn't respect you' (Interview, 7 May, 2010). If residents were relaxed, physicians reasoned, they would be more likely to share information that could assist diagnosis and they would be more receptive to medical interventions. While health care alliances facilitated the delivery of care in this way they also involved more than this. As explained in Chapter 6, a 'health alliance' describes relationships characterized by mutual positive regard, a level of trust and ease in the interaction, and a commitment to the resident as a person. Alliances temporarily ameliorated residents' experience of colonial dynamics, but they took many forms. Many residents responded favorably to physicians (and other providers) who had more relational styles of practice, but as mentioned earlier, alliances also occurred with physicians who had more conventional, socially distant styles. My discussion here focusses on the attributes of alliances that accentuate the relationship and highlights practices observed in building and maintaining these.

Residents saw medical relationships as a means to address various concerns but many derived affective benefits from the relationship itself. It was evidenced by some who commented how interacting with their physician 'lifted' their spirits. Sometimes there was a gendered aspect to this. For example, one female resident described looking forward to visits with a male physician and revelled in his attention, joking, teasing and lamenting the challenges with various men in her life. That a few female residents reported being attracted to male *physicians* and a few male residents reported being attracted to 'cute' (young) female *nurses*, highlights the intersections of hierarchies of gender, class and occupational status. However, I found that the positive impacts of a physicians' visit were often reported by patients of the same sex, which suggests gender may have a more limited influence. My point is that in many instances residents were seeking the medicine of relationship in addition to the medicine of medicine: affirmation, understanding, and reassurance they were not alone. I noticed the power of personhood on residents by the impacts of its felt absence in encounters when the physician had addressed medical concerns but residents later reported feeling unseen, mocked, or treated like an Addict. In some instances, medical concerns offered the reason *to* interact but were not the reason *for* interacting. Drawing on his own experience with a

life-threatening illness, sociologist Frank (2004) described the positive impacts of providers' presence and care as 'moral moments', arguing that these contributed to a 're-moralization' of care.

Relationships with residents could also be a form of medicine for physicians as well. 'The people are amazing', one physician said, 'They're my brothers and sisters, my teachers, fascinating, heartbreaking . . . it's not just about the medicine, it's very, very raw and deep' (Interview, 17 August 2010). Another reflected, 'I've probably become more humble over time and recognize my limitations more than when I first started' (Interview, 10 February 2010). However, it's important to acknowledge the diversity among physicians and of alliances.

Reviewing field data I frequently noticed disjunctures in what physicians believed about their practice as reported to me in interviews, what I observed in their clinical encounters, and how residents experienced their care. For example, a physician who described himself as non-paternalistic, seemed unaware how he sometimes pressed residents to accept medical treatment. Such disjunctures were present in most interactions and my own relationships with residents were no exception. As ease developed in some relationships, several residents began noting when I seemed preoccupied or chastised me when I didn't listen very well. In noticing the disjunctures of medical encounters, there was one exception: the striking *congruence* in Dr. Rivers' beliefs about medicine as expressed in interviews, what I observed in his clinical interactions, and how residents experienced his care. While there were numerous similarities between his practices and those of other physicians, I also observed several attributes unique to Dr. Rivers' practice that helped ameliorate residents' experiences of the colonial dynamics of care, which I describe below. While each physician had patients who reported strong supportive relationships and some who were dissatisfied with their care, Dr. Rivers' patients often made a point of describing how he was different from 'other' doctors and their descriptions of these 'differences', were also strikingly congruent.

To elaborate the factors that can facilitate a health care alliance, I structure my discussion around Dr. River's practices, but draw on data involving other physicians when relevant. I also note that the way providers temper colonial dynamics in clinical practice does not necessarily translate to their practice in other contexts. The point I

want to emphasize is that the power of physicians' personhood, when it leaves residents' feeling seen, heard and cherished, can be communicated through diverse styles of practice.

Let me begin by noting that one idiosyncratic feature of Dr. Rivers' clinical practice was the fluidity of its form. Where most physicians had a fairly predictable way of structuring clinical encounters,<sup>60</sup> Dr. Rivers followed residents' lead and ways of relating. With a resident who needed to feel more involved in directing his care, Dr. Rivers took the role of co-pilot; with a resident who was frequently distracted, Dr. Rivers hopped alongside from topic to topic; and with a resident who preferred to be a passenger, Dr. Rivers led the way: pausing when she had questions, elaborating points of significance along the way, and swiftly turning the trajectory when she casually mentioned 'going blind'. He often used residents' comments and information about their lives as a segue to discussing medical matters. The resultant blending of residents' ways of relating and contributions with physician-identified concerns was described by one Indigenous resident as 'seamless' care. A more common way that residents described physicians with whom they felt an alliance, as mentioned in Chapter 6, was that the physician interacted like or treated residents like 'a normal person'. The significance of normalcy in residents' descriptions of positive relationships might be read as the internalization of normalizing discourses on residents' subjectivities, but I saw it as the deep yearning to exist 'in the ordinary' (Das, 2007, p. 7), free from judgement, regulation and exploitation. In a setting where the social and economic differences were less extreme, and where providers and patients were not so clearly bound in an interdependent, hierarchical relationship of power, residents may have felt more 'normal'. But in this setting, a feeling of normalcy when interacting with an authority was a precious exception and signified a social, moral and affective spaciousness that allowed the resident to 'be'.

Before I discuss the attributes of an alliance, it's important to note their limits. Alliances mediated but did not remove the influence of colonial dynamics: Interactions still occurred within conventional asymmetries and parameters of medical science, physicians' authority, and the medical aims of care. Physicians' concerns and goals still

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<sup>60</sup> This typically followed the pattern of greeting the patient with some 'social time', identifying medical and/or patient needs for the visit, addressing these, updating medications/prescriptions, summarizing key points, and scheduling follow-up.

took precedence. Alliances were also not without complexity. During one Clinic observation, the male resident, 'Tom' turned to me with a twinkle in his eye and said (with the physician – Dr. Hill - in the room), 'Me and her [physician] have a good relationship. She tells me what to do and I do it' (Field Notes, 28 January 2010). Later in the visit I recorded the following field note of their interactions around the topic of medical marijuana:

Tom raises his eyebrows in a mischievous smile and says to Dr. Hill, 'I'm still trying to get on pot'. As Dr. Hill looks at him Tom adds, 'I only asked you once before'. Dr. Hill tells him to get the forms, explains where to get them and then steps out to enlist help with her computer. As soon as she's out the door, the Tom turns to me and says, 'She lied. The last time she said she couldn't see a reason for me to get it'. After returning to the office other topics are mentioned before Dr. Hill begins winding up the visit by asking if Tom has any other concerns. 'Only the pot thing – you know I like my pot – I buy it on the street so it saves me some money'. In response Dr. Hill leans forward with a smile and says on a lighter note, 'it's not good for your lunches' (Field Notes, January 28, 2010).

The warmth of the encounter reflected an alliance that had developed over many years, but their communication around medical marijuana highlighted the political subtext: How far could either of them press their concerns while maintaining the congenial tone of the encounter? Alliances, like any relationship, were not static as long-term alliances could founder and relationships that had been marked by tension or strain at the outset could also improve.

### **9.3.1. Knowledge and humility**

*People constantly exceed the projections of experts. The medicoscientific, political, and humanitarian frameworks in which they are cast cannot contain them. (Biehl & Petryana, 2013, p. 5)*

Although medical science has often been critiqued for its universalism, I found two physicians who had experiences working in other cultural contexts questioned the universality of biomedicine. Living and working in Indigenous communities had enabled one physician to witness how traditional medicine sometimes produced extraordinary improvements in health. From his own experiences in cross-cultural medicine, Dr. Rivers had come to understand Western medicine as a cultural system and recognized that there was no single way to understand phenomenon and 'not one right way of doing things' (Interview, 10 February 2010). He didn't presume to understand how residents

defined their concerns or what they thought would help but knew that medicine needed to align with their social context, understandings and goals. The aim of his care was to meld medicine 'with some sort of value system that suits what the patient is after' (Interview, 10 February, 2010). While several physicians found the provision of medical care required a sense of connection with patients, Dr. Rivers understood this as the need to become familiar with the residents' story.

As mentioned in earlier chapters, several physicians generally alluded to problems associated with the asymmetries of power, such as how the service industry undermined residents' motivation or independence, but did not consider how the imbalance of power in their own practice could also have this effect. Dr. Rivers' understanding of power differed from other physicians in that he integrated his understanding of colonialism and an awareness of physicians' power in the context of his clinical practice. As he told me in one interview, 'There's no question that there's a power differential, but having power and using it are two different things. . . . The power differential is never going to disappear but it's how you exercise that power which . . . makes the difference' (Interview, 10 March 2010). His understanding of power also differed from other physicians in that he tacitly recognized the moral dynamics of care by resisting the application of moral filters that would privilege his values and therapeutic priorities and restrict residents' choices. As he explained to me, 'It's not our place to say this is right or wrong, but it's our place to stay beside them and just care for them . . . as opposed to taking ownership of [their] problems' (Interview, 18 May 2012).

### **9.3.2. Asking and listening**

In response to the problem of 'talking and telling', discussed in Chapter 8, many residents advised providers to spend more time 'asking and listening'. To be clear, physicians asked many questions. While some residents wanted to get 'in and out' as quickly as possible, I did not encounter any resident who objected to a physician (or other provider) who tried to understand their perspectives in the process of addressing their concerns. The questions deployed with talking and telling, generated information that supported medical reasoning, accepted physicians' understandings and aims without questions and, as a result accentuated hierarchies of power. In contrast, 'asking and listening' was predicated upon the physician recognizing the limits of their knowledge, eliciting and weaving residents' knowledge and priorities into care. One

settler resident explained that physicians don't 'know what kinds of change this person might need', and encouraged physicians to 'take it more slowly – just start talking to the person: 'Is there any way I can help?' or 'Can I have a look at your wound?' (Interview, 21 April 2011). 'Asking' acknowledged residents as bearers of knowledge and allowed them to contribute or decline information (Balshem, 1993; Carpenter-Song, 2011). Because residents' responses could not be predicted, asking about their understanding of the concern and what they thought might help opened different possibilities for the trajectory of medical care (Katz & Shotter, 1996).

Many residents attributed the difference of Dr. River's practice to his listening skills. 'He doesn't interrupt you', one soft-spoken Indigenous resident explained, 'he lets me finish. . . . He sits and listens to what you have to say about your health. . . . Instead of him *telling* me what's bothering me – he *asks* me what's bothering me (Interview, 17 November 2009). Physicians demonstrated they were listening by not repeating information or clarifying themselves if a resident declined their assistance. In the talk-intensive context of health care this is difficult to do because providers typically want to know that their helping intentions are understood. For many residents, being a good communicator recognized that silence was also an answer. But silence could mean many things such as resistance, incomprehension, embarrassment, frustration, fear of judgement or rejection. Dr. Rivers responded to moments of ambiguity by affirming residents' responses and following their lead.

According to residents, another feature in Dr. Rivers' practice was the *way* he asked. The art of questions understood the shape and feeling of words and phrasings. Some words and phrasings were hard, with edges that grazed sources of embarrassment or shame. Direct questions, such as why a resident had started using drugs again or was late getting a prescription renewed, carried a blade of judgement which often left residents feeling defensive. It was not the words alone but how their meaning was moderated by spatial distance versus proximity, distracted or full attention, body language and tone. Hard approaches often lacked an alignment of these elements or failed to adjust these by anticipating how the resident might experience the question. Most physicians were attuned to this and when I observed hard approaches, it was usually in regulatory areas of practice. Dr. Rivers, however, used soft approaches across the spectrum of concerns. The following field note illustrates his use of open-ended

questions, phrasings, affirmations, tone and body language to inquire about a traumatic injury incurred by a resident I refer to as 'Jude':

Sliding toward Jude in his chair and leaning slightly forward he lowers his voice, 'how's your shoulder?' The corner of clean dressing applied by the Clinic nurse is poking through the neck of Jude's top. Leaning forward and looking directly at Jude with concern, he quietly asks, 'Can you tell me what happened?' All she remembers is waking up in the hospital. He notes that she's struggled before, tentatively adding that things seem to happen when she's been drinking. His attention and tone remove any question of judgement. He asks how she feels. Jude doesn't answer directly but explains what triggered the fight. He listens carefully. When she's finished, he asks if it might help to talk to someone. Jude isn't sure: she needs to know them and feel comfortable with them first. It's important, Dr. Rivers, agrees. Non-committal, shifting in her chair, Jude changes the topic. He doesn't press, and the visit moves on to other topics. (Field Notes, 23 February, 2010).

Prefacing his inquiry with, 'can I ask' indicated what was to follow and gave the resident the power to halt the inquiry. As mentioned in Chapter 6, residents sometime felt caught off guard by providers' questions and, without time to consider their response, they sometimes shared information that left them feeling exposed and vulnerable. Asking and listening, communicated respect for personhood by giving residents' a greater sense of control over their disclosures.

Several residents also praised Dr. Rivers for 'explaining everything'. As one said, there was 'no bullshit, [he] doesn't try and fool around things, he just tells you right there what you need to do if you want to help yourself.' (Interview, 15 November, 2009). Initially this confused me since other physicians also spent time explaining information. While praise for straightforward explanations was not limited to Dr. Rivers, reviewing field data I noticed several things. Other physicians frequently explained medical diagnoses and treatments but not the medical reasoning for what they were ruling in or out or for offering or withholding particular interventions or medications. As well, in the overall context of the encounter, residents' priorities, concerns and 'air time' were often subordinate to physician-identified priorities and 'talk'. Since physicians ultimately controlled how much time was spent on each visit, when physicians took time to explain medical matters it often meant less time for the residents' perspectives and concerns. Like other physicians, Dr. Rivers had various things that he wanted to address in each visit, but he made a point of ensuring that residents' concerns were heard and

addressed within the visit, and usually did so as they were mentioned. This occurred in encounters with other physicians but was less consistent since residents' health work often involved waiting for the appropriate moment to broach their concerns. If the physician was pressed for time and started bringing the visit to a close, residents often held their concerns.

The importance of having everything explained went beyond the content or comprehension of what was said. One Indigenous resident told me she didn't always understand Dr. Rivers' explanations but she 'liked listening to [him] talk' (Interview, 17 November, 2009): Care spoke through his presence, words and body language. Lazarus (1985) found women's objections to medical care were based on the 'manner in which they were treated' and the disregard, not of their knowledge, but of their dignity (p. 46). I found this true for many female *and* male residents, particularly for those who were Indigenous. As Stevenson (2014) and Simpson (2017) state, '*who*' the person is matters intensely.

### 9.3.3. Presence

For many residents, a salient indicator of an alliance was how they *felt* during and following the encounter. When I asked one Indigenous resident what it was about her physician that placed her at ease, she replied:

She reminds me of a deer. She has such soft, gentle, smiling eyes. And if you ever look at a deer's eyes – that's how she is . . . there's just a calmness about her. . . . Other ones you can just feel they got a great big wall . . . you feel it as soon as you walk into the room [while jolting her upper body for effect] (Interview, 7 April 2011).

In Chapter 6, I discussed that several residents described their physicians 'like a friend' or described having a 'comfort zone' with their physician. The personal significance of an alliance was eloquently described by the following resident:

I feel like I'm comfortable – how do you put it, like 'I'm at home' kind of thing [laughs], like I'm talking to a friend. Yeah. I think it's his attitude. He's very cheerful, very upbeat, happy and I think that might be it. I see that it helps me because I'm a very quiet person and it's hard for me to talk to people. Always has been, so for me to click with someone and be comfortable like that . . . it's pretty good, doesn't happen very often (Interview, 10 November 2009).

The felt quality of a physicians' presence often reflected physicians' response to the temporalities of care. Indeed, another frequent source of praise for Dr. River's was that 'he took the time' and didn't rush patients out of the office. As discussed in Chapter 8, when residents felt rushed through visits, they often felt disrespected and that the provider did not care or value their time and the inconveniences incurred in accessing care. When a physician 'took time', it communicated that they saw the resident as worthy and usually left the residents feeling seen, respected and valued. Even if residents didn't understand physicians' explanations, taking time reduced the chance of residents' attributing physicians' actions to their desire to control or profit from residents' lives. When physicians' presence enabled residents to relax and be themselves, little if any health work was needed. However, it is important to note that several physicians would have liked to take more time with patients but felt pressured by their awareness of those waiting to be seen and their desire to make medical resources available to as many patients as possible

#### **9.3.4. Going the extra mile**

The importance of a positive presence and the readiness to 'take time' converged in physicians' readiness 'to go the extra mile'. This is exemplified in the following quote where the male resident, quoted above, explained why he was 'sticking' with Dr. Rivers:

He took time, he cared for me as a patient and as a person. He hoped that I [would] get better and [that] I understand what's happening . . . and [he'll say] 'I would like to help you do it'. Great! Like today, I've been denied twice for my disability, so I mentioned I want to do my disability [application again] and he goes 'no problem, get the paperwork and we'll set up an appointment right now' (Post-Observation Interview, 10 November 2009).

Medicine is an action-oriented profession in its quest to solve problems. The difficulty was that physicians often took action on issues that were not of greatest concern for residents. When one physician went to extraordinary lengths to obtain an ARV that one resident could tolerate, the resident wasn't moved because she saw this as part of the physician's job. Instead, 'going the extra mile' registered in things that carried significance for residents, such as visiting them in hospital, a home visit when they were too ill to get to the Clinic, advocating for them with other authorities, attending memorials, and being happy to assist their applications for benefits, even two, three and

four times. For some residents, it was only when a physician went the extra mile that they started to believe the physician *really* cared. When the relationship itself was experienced as medicine, going the extra mile could increase residents' receptiveness to medical concerns.

One Indigenous resident, 'Ed', booked an appointment to get medication for back pain. In the course of the visit I observed, Dr. Rivers addressed Ed's smoking, physical fitness, drug use, adherence to ARVs, weight, depression, and the flu vaccine. Just as Dr. Rivers often used residents' questions and comments as a segue to medical matters, residents often used Dr. Rivers' questions as a segue to sharing stories about their lives. In this visit, the inquiry about smoking prompted Ed to share a story about an incident that led to jail time, having his tobacco taken away, starting to exercise in response, and later noticing how his endurance had improved. In response to the inquiry about drug use, Ed said that reducing his drug use was the hardest thing he'd ever tried and added, for emphasis and levity, that given the difficulty of reducing his cocaine use he'd rather be 'dumped by a thousand women'. When a flu-vaccine was broached, Ed asked Dr. Rivers' views on media reports of mutations in the flu virus. This not only demonstrated he was active, informed or intelligent, but conveyed his recognition that Dr. Rivers embraced these attributes. In my post-encounter interview, Ed said he felt the visit had gone well, pointing out that he'd gone in to get T3s for his back pain and a flu shot and ended up with a hearing test, a lung x-ray and a test for lung capacity – evidence of the extra value he'd derived from the encounter (Post-encounter Interview, 5 November 2009). The reason Ed saw the inclusion of medical matters as extra value came from knowing the Dr. Rivers' respected his intellect and personhood. This respect was conveyed in the way Dr. Rivers' broached the topics, in his recognition of the value and the gift of Ed's stories, and in the evident pleasure he derived from interacting with Ed and other residents (something which several physicians conveyed). Being open to residents' stories, which required physicians' to relinquish some control over the encounter, avoided the erasure of personhood amid the temporalities of care. Going the extra mile involved extra effort on behalf of a physician, but when there was space for residents to exist as persons, they too sometimes went the extra mile by sharing information about their lives to ensure that mile was a satisfying mile for both parties.

### 9.3.5. Restoring choice: Self-determination

Consciousness about power relations was tied to Dr. Rivers' recognition of the fundamental connection between respect, self-determination and well-being. The perspective was informed by his experiences working in Indigenous communities. As he told me, 'What I've observed about Aboriginal cultures is [that] they're very respectful of other people's decisions – like you're often allowed liberty to make your own choices and stand or fall as a result of them'. He then related this to his interactions with residents, saying, 'it's a question of not being judgemental and being unquestionably supportive regardless of the situation' (Interview, 10 March 2010).

Other physicians talked about the importance of respect and self-determination, but as I discussed in Chapter 8, this was often compromised by the application of moral filters that reduced residents' choices and autonomy. Dr. Rivers tried to privilege residents' preferences even if, at times, it meant jeopardizing medically desired outcomes. Respecting residents' right to self-determine was helped by providers being able to imagine themselves in the residents' position. This is apparent in the following interview excerpt, where Dr. Rivers explained the rationale for his response to a resident, 'Mike', who requested to take his ARVs at home:

Mike didn't want to have someone on his back every day telling him to do something. . . . I think [having his ARVs at home is] a bad idea, and I continue to think it's a bad idea, and I've got the lab data to show that it's a bad idea – but by the same token he wants to do it and it's an expression of his autonomy. . . . I don't want him to wind up developing first line drug resistance and having to go on more complicated [ARVs], which he will more likely fail on again and [will put] him on that road to becoming untreatable. . . . [But] my job is not to be autocratic, my job is . . . to facilitate what you want in the best possible way. . . . Mike was clear what he wanted and I could accept it [or not but] . . . my hierarchy of priorities is [that] I have a good relationship with this person so that he'll come in when he has a problem and when he's in need. . . . Trust has got to flow both ways – he's got to feel that I trust him. . . . Me saying 'I don't trust you taking your medications by yourself', it's somewhat of a blow to his [self-esteem] (Interview, 29 May 2010).

By prioritizing a resident's self-determination while knowing there was a good chance of compromised outcomes, Dr. Rivers accepted a level of risk not only for the resident but also for himself in the possibility that colleagues might question his judgement. While several physicians acknowledged the need for some give and take in the context of

prescription practices, I observed that many were less willing to take risks if it meant compromising HIV care. The openness to residents' views and the flexibility in adjusting his practices accordingly were a feature of Dr. Rivers' practice.

Dr. Rivers' willingness to support residents' preferences was finite, but he tried to give several warnings before initiating a change. This was illustrated in a visit with an Indigenous resident I refer to as Jody, who had mobility challenges and mentioned during the visit that she was now able to walk for several hours. The following field note was made at the end of the visit when Dr. Rivers was renewing prescriptions and asked where she was getting her methadone:

Jody still wants it delivered. He asks how delivering [her medications] is helping her. She said pharmacy staff remind her about her appointments. Dr. Rivers explained that he doesn't want to stretch the pharmacy too far. If she's now able to walk 3 hours that's awesome – she could probably get to the pharmacy. He agrees to home delivery adding there would come a point when she will have to come and get her meds. (Field Notes, 17 November, 2009)

Rather than framing his response in a way that might convey judgement by inferring the misuse of resources, Dr. Rivers framed his concern around placing additional demands on the pharmacy. In this way he shared his rationale for any future change while showing it wasn't personal. He still held the power, but not stopping deliveries on the basis of the disclosure of how far she could walk avoided her feeling that information shared in trust was used against her: something many residents referred to as 'being punished for telling the truth'. It also gave her the option of subsequently exercising some control by announcing she no longer needed deliveries.

Several physicians sought to mediate the difference of power by the transparency of medical information. Computer screens were often turned so residents could see their records, results of lab-work, and specialists' reports. Physicians were often called upon to complete applications for residents to obtain various benefits, but I only observed one medical visit, which happened to be with Dr. Rivers, where the physician's responses on a form were discussed with the resident. During the visit, he took several minutes to explain what he had written about the resident on the benefit application. When I later inquired why he had spent the time on this, he explained that if another provider subsequently shared what he had written with the resident, he didn't

want her to be surprised or think he had betrayed her. Transparency communicated respect through a commitment to 'no surprises'.

While residents' preferences are diverse I found that more residents, particularly those who were Indigenous, preferred physicians who took a more relational approach to practice. But I also met residents (Indigenous and settler) who were vocal critics of providers' governance yet had close relationships with providers who had more paternalistic styles of practice. One Indigenous resident, 'Alice', who described her physician, 'Dr. North', as 'like a dad', had never had a reliable or supportive parent. Although her independence and resistance to being judged or controlled had often made it difficult to access health services, when describing the relationship with Dr. North, Alice told me:

He always brings me up, like [he'll say] 'you're doing good, I'm proud of you'. He never puts me down. . . . If you do something wrong he'll tell you right there. . . . He's my life saver. Every time I see him I'm always happy (Interview, 28 December 2010).

The alliance had offered stability, consistent support and affirmation through many trials, and had, quite literally at times, been her 'life saver'. Likening Dr. North to a dad signified a relational refuge where she could relax into his care, confident of his commitment, support and positive regard. The importance of self-determination in an alliance, then, did not exclude paternalism and at times met the yearning for relational shelter. There was also more to this. The importance attached to the fact Dr. North 'always brings me up', mirrored Alice's own strong values and commitment to encouraging counterparts who were struggling. Although paternalism is encoded in the colonial dynamics of care, Alice's comments show that it is not unitary or definitive and is mediated by other factors in residents' whole experience of the encounter and history with the provider and the resonance of these with their own values of care.

#### **9.4. Building connection and community**

In the public spaces like the Clinic reception and Drop-in, where interactions were often fleeting and occurred in public, the power of personhood was often less about building alliances than in creating a space that facilitated and sustained residents' engagement in care. The ability of providers to recognize and interact with residents as

persons in these settings was influenced by the socio-structural context, their roles and their understandings of these. As I discuss factors that facilitated residents' engagement in open settings, it's important to note the diversity of both settings: some providers had little interaction with residents even when time permitted, some residents remained unseen, and some residents preferred it this way. In this section, I concentrate my analysis on the Clinic reception area.

In the Clinic reception the industrial temporalities and structures of care constrained reception staff in being able to recognize and interact with residents as persons. Given the noise, interruptions and stress of the reception, I was less surprised that staff might be brusque at times when interacting with residents than that they maintained an overriding desire to assist residents despite the challenges of their roles. When I asked the clinic manager what contributed to the enduring desire to help, she replied:

I think it's partly staff morale: If they feel good about working there and have good relationships with their co-workers, they feel better about stuff and they can project that onto patients. But [it's] also because they come with a caring heart right from day one (Interview, 5 November 2009).

As mentioned in Chapter 7, good morale was a result of staff feeling accepted and respected as individuals, and as valued members of the Clinic 'team'. Morale was also a testament to the collective powers of personhood and the 'caring hearts' of all staff. Just as the warmth at the interface of care in reception was facilitated by the collegial relationships among providers, the culture of the Clinic was facilitated by the executive director's respect for the competence of Clinic providers and their ability to run the Clinic. As observed in many health care interactions, exerting less control over others' behavior often encouraged more presence, vitality and engagement. In terms of how that translated on the ground, for many residents the main difference of this Clinic to other clinics was the friendliness of staff. The significance of 'friendliness' cannot be underestimated as the following resident explained:

[Providers at the other places down here say] 'what do you need, what do you want, this is what we'll do for you but you gotta follow this, you gotta follow that, OK come back and see us on this day. Next!' [Here, at Native Health] They take time, they take the time to work with the person and actually do it with a smile on their face, like they'll go out

of their way. I've seen them do that with a few people. They've done it for me (Interview, 13 April 2010).

The generative power of personhood in the Clinic mediated but did not eliminate asymmetries in power. Providers still set the parameters and objectives of care (and in most cases with little to no input from residents), and were more able to express their individuality and critiques. The expression of residents' agency and critiques, in contrast, always risked being attributed to the behaviors of Addicts. Still, with these differences and contingencies in mind, the power of personhood in the Clinic reception area became visible in efforts to make residents feel welcome, in the spirit of generosity, and in the importance of familiarity and providers' readiness to 'be human'. Woven through these, as in the Drop-in Centre and medical encounters, was the humanizing influence of affection, humour, and laughter.

#### **9.4.1. Welcoming**

Across the Vancouver Native Health Society (Native Health), most providers recognized the importance of making residents feel welcome. A welcoming environment for residents was an environment where providers appeared to enjoy their jobs, interactions with residents, and took extra steps to assist them as they were able. Even if residents weren't directly engaged in conversation with staff they were able to observe, overhear, and hence, be vicariously included in the banter between staff. The informal and cooperative nature of relationships among providers in the Clinic tempered the occupational hierarchies and social distance that tended to characterize the relationships between physicians and reception staff in other clinics. The Clinic reception showed that even in a highly structured setting, when providers feel respected and able to be themselves it creates the conditions where they are more likely to recognize residents' personhood. In addition to greeting residents by name and the expressions of affection that often accompanied this, staff acknowledged residents as persons through spontaneous gestures, like bringing out paper and crayons to occupy young children or sharing food among patients in the waiting area. These gestures, as shown in the following field note, created ripples of warmth among those waiting:

[Reception Staff] was passing chocolate cookies around to the patients in the waiting area. She offered me one and I declined. Seated beside me, Susie whispers 'you could have taken it and given it to me!' I quickly called [the staff person] back, took a cookie and broke it,

giving half to Susie and half to Rhonda seated on the other side of me. Suzie's doctor came out a few minutes later and called her in. Suzie is holding her cookie in one hand and a crossword book in the other as she follows him to his office (Field Notes, 23 February 2010).

Stability in staff, as mentioned in Chapter 7, also contributed to a welcoming environment because interactions over time helped each party to know what they could expect from the other. It was stressful for many residents to access services when they didn't know providers, even for residents familiar with Native Health. Because when providers didn't know residents, it was more difficult for them to interpret residents' behavior and adjust their practices accordingly.

## **9.5. Generosity: 'A caring heart'**

A 'caring heart' reflected a generosity of spirit that, like the examples noted above, was expressed in an array of gestures and personalized forms of care. It was observed generally in providers' acceptance of the special connections that formed between individual staff and specific residents, and in the absence of cliques among providers. It was also evident, as in medical interactions, in the readiness of staff to go beyond their formal roles to assist. Stories of these occasions were recounted to me with pride during interviews and included locating residents after work to deliver important information, transporting residents to and from the Clinic if they were ill, disabled, or elderly, and, in one case, working with the administration to obtain bus fare for a young Indigenous woman to return to her reserve before she became enmeshed in street life. These stories told a larger narrative: that in this clinic, reception staff were not mere functionaries, they were also persons and providers who cared about residents as persons. The clinic manager sometimes questioned these actions but did not block staff, conveying respect for the diversity of their relationships with patients and for the more personal expressions of care that could flow from these relationships.

When residents felt recognized as persons they were brought into the sociality of the setting and were more able to express their personhood and acknowledge the personhood of providers. In the reception area, residents expressed their individuality in humour, assisting counterparts with mobility challenges, helping staff with sundry tasks, and occasionally with surprise visits or unexpected gestures of care. One summer afternoon, a resident well known to staff burst through the main door with her hair, face

and overalls splattered in blue paint, and held out a bouquet of flowers for staff. A moment later she turned and just as quickly exited, leaving one resident to muse whether he'd just seen a Smurf (a fictitious blue figure with human qualities). Although I observed it more often in the Drop-in Centre, residents also demonstrated their care for providers by assisting or intervening when another resident was 'out of line'. I saw residents' decisions to access care not only as a response to medical need but as an expression of generosity: Residents recognized the economic capital represented by their bodies and that providers' employment depended on their need. There were other options for medical care, so it was significant that they chose to obtain these services at Native Health.

## **9.6. Moral violence and the burden of care**

Although my focus in this dissertation has been on residents' experiences of care, some data showed that colonial dynamics also had negative impacts for the personhood of providers. The political struggles between agencies and health care reforms, as one physician observed, involved 'a lot of violence in human values' (Interview, 22 June, 2010). In Chapter 6 I discussed how providers who challenged the conventions of professional boundaries sometimes found their jobs and reputations in jeopardy. And in Chapter 7, I discussed the moral distress some reception staff felt in having to turn away residents when the Clinic was full. In this section, I discuss the burdens of caregiving as responses to the colonial dynamics of health care.

Providers often referred to the embodied – affective and physical – burdens of care as 'burnout'. The signs of burnout varied but included becoming hardened to residents suffering, starting to resent or hate residents, emotional and physical exhaustion, withdrawing from family and friends, increasing rigidity and irritability, and losing enjoyment in activities that once gave them pleasure. Providers who shared their experiences of burnout with me usually attributed it to the excess exposure to (and embodiment of) residents' suffering, failing to maintain 'good boundaries' between work and their personal life, and inadequate balance in their lives outside of work. Regardless of contributing factors, experiences of burnout often led to medical leaves which offered time for reflection and, for some, turned their attention to sources of emotional pain in their own lives. One such provider subsequently came to understand that she had

externalized her pain and tried to address it through caring for residents. Her comments hinted at the ‘addiction to care’ described by another provider in Chapter 6, which recognized how providers’ response to their own sources of emotional pain were not unlike the reasons many residents gave for using illicit drugs.<sup>61</sup>

I contend that the burden of care, like the institutional sources of residents’ suffering, is produced by colonial dynamics which inflate the importance of providers’ knowledge and responsibilities beyond what was actually possible for them to know and to address. One physician found that sharing decisions with residents lessened the weight of her professional responsibilities. Other times, providers had the knowledge and technologies to fulfill their responsibilities, but residents declined the help. When therapeutic aims were thwarted, the providers’ responsibility and duty *to care* became the burden *of care*. Tied to this is the fact that providers’ personhood is subordinated to the precepts of professionalism, which value specialized knowledge and skills. Most providers in this study were reluctant to express their unknowing, shortcomings, or the constraints on their practice when interacting with residents. There are many reasons for this but suppressing or silencing critiques and human responses to residents’ suffering does not erase the limitations and harms of care, nor the negative impacts of colonial dynamics for residents and providers alike, but instead ensures it. As Briggs (1996) wrote:

Humanity is gained as the world, in the spaces between people, is acknowledged rather than denied or pushed away. When there are attempts to push away or ignore the world, the realities of power difference that constitute the public realm still influence relational interactions but do so underground (p. 6).

## 9.7. Reporting back

In the last year of writing, two Indigenous residents with whom I maintained ongoing contact chastised me for ‘taking so long’ and to ‘hurry up’ and finish the dissertation as those who participated in my study were rapidly dying. When planning my

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<sup>61</sup> The greatest strain for some physicians was the ‘health care system’ in terms of unsupportive supervisors and reforms which promoted rigidity and of the needs of computer systems over flexibility and relationships with residents – factors that were among those identified in McKinley and Marceau’s (2008) study exploring the declining number of primary care physicians.

trip to the DTES to determine how best to share my results, I sent notes to several residents. An unexpected phone call from one Indigenous resident, 'Mary', affirmed my decision to exclude the Drop-in Centre from the dissertation and also underscored the complexities of research relationships in studies like mine that sought to adopt an ethic of collaboration. Having received my card, Mary challenged me, saying:

who are you going to talk to, most of us have died! You're just like any other white person who thinks they can just swoop into our lives, telling us what we need. What you studied [in the Drop-in Centre] is history now – who is it going to help! No-one is going to read it. [LC: what do you want me to do?]. Burn it! Burn it! It means nothing now. You have no business coming here. I'm going to tell [the new coordinator of the Drop-in Centre that] everything you wrote is bullshit. Give it to the people to get your paper but it's just another useless study, burn it! (May 31, 2018).

After hanging up abruptly, two more calls followed in quick succession. Answering these I began to understand the layers of her concern. Four years ago, after reading an early draft of a chapter about the Drop-in Centre, she had chastised me for not condemning the behavior of provider who was, in her words, 'a tyrant'. Then, as now, I was unable to convey the complicated constraints on staff, my personal debt to the agency (and to the particular individual concerned), and my ethical obligation to prevent harm to residents and providers. In her view, I had betrayed residents by 'not telling the whole story'. But her critique of me was also not the whole-story of her frustration. She felt I had abandoned the Drop-in Centre by not fighting for its existence and, as a white person, that I could not possibly understand the realities and struggles of residents' lives. (I agreed). She wanted me to 'tell the whole truth' and 'fight' for the Drop-in Centre, while rejecting me as one more white person who 'swooped' into residents lives then left the area to resume my comfortable middle-class life elsewhere. She had been through two exceedingly difficult years which, in my view, heightened significance of the Drop-in Centre as source of stability and community. On the third call, she thanked me for answering the phone and conceded that I was a 'good person' but remained 'pissed off' that I could not (or would not) tell the 'whole truth' of what I had seen and been told by residents. On this, she assured me, she would not change her mind. We then talked about other things including the pain of losing a dear friend who had fought for justice and didn't hesitate to speak truth to power. Feelings of loss rose to the surface. In standing up to me, a figure of all whites and their oppressive benevolence, she took a symbolic stand beside her deceased friend in fighting for justice and truth. But it wasn't

so straight forward: knowing I had been close to this friend, she told me our friend had always – only - ‘used’ me for what she could get from me. It hinted at more complicated subtexts that I had sensed during the preceding months. When I continued to include Mary in the plans for circulating the findings to residents in the Drop-In Centre, she acknowledged she had been ‘hard’ on me and apologized, then quickly added that it may have been necessary to ‘get through’ to me.

I subsequently presented findings in two presentations: one for providers, which was attended by Clinic staff, administrators and two providers from the Drop-In Centre, and the second, for residents in the Drop-in Centre. At the presentation for providers, awareness of my dual accountabilities to residents and to Native Health unsettled me. Prior to the first presentation I touched base with the clinic manager, two physicians sharing the role of clinic coordinator, the chief operating officer and the executive director (ED). All assured me not to worry, but I was particularly struck by the ED, Lou Demerais, who immediately and firmly encouraged me to share my critique without fear of negative responses, stating that providers needed to hear residents’ perspectives and it might help to improve services. My fears were juxtaposed with the ED’s readiness to embrace critique. His comments reflected what I’d observed among many residents, and particularly Indigenous residents, which was a readiness to have sensitive aspects of their lives included in the dissertation because ‘it’s the truth’. When setting the date, the chief operating officer, Robyn Vermette, immediately said a catered lunch would be provided, which situated my work in an affirmation of community. Following the presentation several providers expressed a desire to translate findings into practice, with Lou Demerais adding that the findings could have relevance to providers beyond Native Health. While none of the physicians were able to attend the session due to workload or other commitments several had expressed interest in reading the dissertation or promised to be in touch at a later date. When the session concluded, Lou Demerais, presented me with a magnificent wooden rattle carved by Andy Wesley. I was honored to accept this gift and I understand it as a testament to the generosity of Indigenous Peoples’ generally and to Native Health and their support for this study.

The presentation for residents confirmed the ongoing reality of their general critiques with several offering stories of their own interactions with physicians as further examples. Residents’ comments also reinforced that the critiques of the Drop-in Centre, which I had documented during fieldwork, were now out of date. Several residents

(including some I had not met previously) stepped forward to thank me following the session.

## 9.8. Conclusion

I have argued that broader processes of colonialism are enacted in everyday relationships between providers and residents, but I also recognize most providers are doing their best in exceedingly (and increasingly) difficult conditions. As mentioned, when residents praised providers for relating like a normal person, they were often responding to exceptional care. Yet exceptional care is still a humble and contingent offering. I found most providers overestimated the contributions of health care in alleviating residents' suffering and in its ability to influence health inequities, and most providers had difficulty seeing how their own practices and moral aims could harm. Residents' critiques expressed a deep yearning to feel treated like a person, to have their privacy, priorities and right to self-determination respected, and to feel they mattered to the provider.

Health care alliances attested to the ability of providers to ameliorate colonial dynamics in some ways but there is only so much providers can do within the existing dynamics and structures of health care. Is creating a less colonial experience of care good enough when the foundational injustice of colonial occupation and governance remains unchanged? How will improving the experience of health care in a system that is fixated on professional expertise, pathology, and a medical vision of health improvement cultivate respect for human diversity, experiential knowledge, and idiosyncratic desires? How does one address limitations without perpetuating the problem-solving tendencies of colonialism? Are there ways to re-imagine health care relationships as treaties premised upon recognizing patients' personhood, integrating their knowledge, and more fully realizing their right to self-determine?

One of the first steps, identified by numerous scholars, is to change our conditioned colonial ways of thinking (Alfred, 2009; Maracle, 2015; Regan, 2010). Some scholars imply that it is possible to liberate oneself from the 'false assumptions of superiority' but I have argued that colonialism is perpetuated by more than thoughts alone. I have come to see colonial conditioning as encompassing, enduring and seductive. For myself, I accept that there is no point where the condition will be undone.

Although I understand colonialism and its dynamics better now, paradoxes and contradictions persist. Research was the vehicle for my relationships and learning, but in the process, the health research industry and corporatization of health care has become highly problematic for me. The Truth and Reconciliation Commission's Calls to Action (2015) have created a moment of unprecedented public, professional and institutional openness to considering the profound and ongoing impact of colonialism for Indigenous Peoples. Yet the Calls to Action do not address the colonial dynamics of disciplinary knowledge, professional norms and moralities, and of institutions themselves. Institutional initiatives to 'indigenize' health care through promoting 'cultural safety' or increasing the recruitment of Indigenous providers are important but largely disconnected from the pervasive, structural and institutional encoding of colonial dynamics which also, increasingly, constrain providers (Epstein, 2017; Sweet, 2013, 2017). As Dion Stout and Downey (2006) ask, 'Will cultural safety be real or will it be another form of paternalistic control disguised as a panacea approach for Indigenous Peoples?' (p. 332). Growing institutional support for cultural safety co-exists with neoliberal reforms that have increased nurses' workloads, with the result that efforts to cope with excessive demands, rather than ways to improve care, take precedence (Browne et al., 2009; Spitzer, 2004). There are now more academic postings for nursing and medical faculty with interests in Indigenous health, but applicants are still required to have an established 'research program'. What if Indigenous Peoples and communities don't want more research? When Leanne Simpson (2008) asked the people in her community, she quickly learned 'people did not see a need for "research"' (p. 82). I share Simpson's (2011) concern that without fundamentally altering the asymmetries of colonial power, efforts to 'indigenize' may end up appeasing liberal sentiments while leaving the structures of power intact. For Monture-Angus (1999) 'There are no immediate or simple answers. The commitment required [for a renewed relationship with Indigenous Peoples] involves understanding that change will come in small steps. . . . Solutions cannot be articulated as the walk has just begun' (p. 35).

### **9.8.1. Methodological reflections**

How do my methods and findings align with the principles of 'ownership, control, access and possession' (OCAP) that guide non-Indigenous health researchers' engagement with Indigenous peoples? Although I discussed OCAP to some extent in

Chapter 3, my interest here pertains to my findings as a settler and sole researcher and, related to this, how my research process affects the applicability of these findings in health practice.

There is no doubt in my mind that meaningfully engaging residents in research will increase the legitimacy and relevance of findings but what constitutes meaningful engagement? The length of time it took me to recognize residents' main concerns, shows that researchers' and residents' priorities, like those of providers and residents, are not necessarily the same. I've explained in this dissertation how my focus on HIV throughout the study was an obstacle to recognizing residents' main concerns with health services. These challenges, while not unique to this study, are sometimes addressed successfully by the use of advisory committees. However, when I broached the idea of establishing a resident advisory committee at the beginning of this study, my dissertation supervisor, Dr. Dara Culhane, encouraged me to wait and see how fieldwork developed. Her guidance was prescient.

After many months of observing and listening to residents describe their involvements in studies and other initiatives, I began to understand that the anticipated benefits of a resident advisory group for this study were uncertain. Principles of OCAP are fraught in the DTES where there is an absence of unanimity among residents concerning who is authorized to represent them. The elevated status of an advisory role can encourage resident-advisors to see themselves as spokespeople, while counterparts with different perspectives, who might contest advisors' authority and remarks or offer different views remain unseen and unheard. The contributions of an advisory group are also influenced by the social context. At the outset of studies in the DTES, researchers like me, who have little understanding of the area may recruit residents who are more skilled at positioning themselves for such opportunities but have difficulty fulfilling the functions that researchers envisage for these roles. I observed how the social dynamics between resident-coaches in the agency study I evaluated, influenced who spoke more and less and what was said and left unsaid in their weekly meetings. The influence of residents' poverty is significant. I found that residents viewed their involvements with studies and other projects as work, and many know that 'good employees' are more likely to be invited to participate in subsequent – income generating – initiatives. When residents' contributions functioned as health work, it often came at the expense of critique and candour. Other considerations also come into play.

When a subset of residents were selected to participate in special initiatives it invariably elicited charges of 'favoritism', thereby reinforcing experiences of inequity and exclusion among those who were overlooked and creating an informal hierarchy among residents. Being seen to incorporate the guidance of advisors is important for researchers in communicating respect and in building residents' trust, but the accountabilities to a resident advisory group could have made it more difficult for me to elicit, include and represent different perspectives as I met and interacted with new residents throughout this study. While a resident advisory committee may have enriched my study and enhanced the legitimacy of my findings with external audiences, considering the challenges it is quite possible that it could have added complexity with few benefits, weakening my credibility and the strength of my relationships with residents generally.

Having said all that, if distance and resources had not been constraints after I left the field, a resident advisory committee could have been helpful during the process of analysis. Given my positionality as a settler and my findings about the correspondence between residents' critiques and critiques of colonialism, an advisory committee comprised of Indigenous residents and Elders could have strengthened the integration of OCAP principles with my study, enriching my analysis and theoretical contribution. Yet, I would have struggled making such a decision because it would have been in tension with the fact that I included Indigenous and settler residents and the findings reflected their collective contributions. Based on conversations over considerable time, I believe that many residents (Indigenous and settler alike) would have objected to the exclusion of settler residents' and that some of the Indigenous residents I would have recruited for an advisory role would have viewed an Indigenous advisory body as discriminatory

Providers were the other group of participants in this study and provider-advisory groups with other studies not only lend legitimacy to findings but facilitate the integration of findings with practice. However, given the asymmetry in power between residents and providers and the need to avoid privileging providers' views, I never considered the use of a provider advisory group until it was broached by an examiner at my defense. Even as a sole researcher, residents were often suspicious that I was reporting their remarks to providers. The use of a provider-advisory group could have intensified such fears, jeopardizing residents' trust and discouraging their disclosures. Being a nurse, my perspectives were already shaped by a providers' lens and no matter how I might try to bracket the contributions of a provider-advisory group, with the collaborative aspirations

of this study I know their guidance would have influenced me and could have made it more difficult to depart from my original focus on HIV. With the study complete and with my re-entry to nursing in process, I find that many providers now reference colonialism, related 'trauma' and the importance of 'culturally safe care'. I have not yet found a space where it is possible to consider how this study might challenge or extend what they know and how they practice. In this respect, if there was such a thing, a 'post-study provider advisory board' would be immensely helpful in translating the findings into practice.

Meanwhile, my study does suggest several ways for health researchers to increase the relevance of their work to practice. It shows the importance of researchers taking the time to build and maintain relationships with providers and particularly the subjects of care. It also encourages researchers to consider and embrace the limitations of their knowledge and question their research aims, by evaluating these against the views of participants. In addition, this study underscores the value of embedding flexibility within study designs to ensure space for unanticipated and novel perspectives. Conducting research in these ways requires researchers to relinquish a level of control by recognizing participants' as knowledge-bearers and by adopting the stance of engaged co-learner rather than expert-architect-overseer. These remarks suggest that increasing relevance of research to local realities is not unlike efforts to increase the relevance of health care to residents in this study: it involves a commitment to keeping participants' knowledge and priorities at the forefront and accepting that even the most carefully executed study does not preclude the situated, contingent nature of its findings. What I mean is, I now have a better understanding of ongoing colonialism and its impacts in a particular urban setting, but my findings also reflect limits inherent in my positionality as a settler and as a nurse. I will never know what it is like to be Indigenous and poor and have one's life regulated by a multitude of authorities, or what it is like to be dependent on illicit drugs and engaged with street-life. This study offers one story at a particular historic juncture in the DTES. How these findings relate to other health care settings, like rural areas, reserves, and health authorities, has yet to be determined.

I have critiqued colonial categories and discussed how my use of the categories of 'resident' and 'provider' in this study has reinforced these categories. The easement, for me, has come with realizing that a response to colonialism involves an ongoing process of reflection, acknowledgement and accountability, and that complexity and contradiction

are unavoidable. I've learned some things and keep having to learn them again and again. Reflecting on the early months of fieldwork, I recall how seriously I took myself, how irritating it was, at times, to realize residents were smart and agentive, and how afraid I was to relinquish my beliefs and control. Seeing residents and my relationships with them more realistically was freeing. It allowed me to be more honest with residents and respond to their efforts to make money without defensiveness, surprise or judgement. At least if these feelings surfaced, I was better able to locate the problem in my expectations, beliefs or fatigue. It has also allowed me to acknowledge my own colonial tendencies more honestly, tempering the shame that often comes with openly acknowledging the gap between one's practice and colonial ideals of 'professional competence'. Stepping out of my role as nurse relieved me of the professional responsibility and duty to 'improve'. And stepping into the role of anthropologist and delving into critiques of colonialism opened a space that enabled me to see the brilliance of residents as whole human beings. I warred when numerous people approached me for a toonie and was cautious where, when, and how I placed trust. But overall, I was moved by the absence of residents' self-pity, humbled by their trust, and delighted by their irrepressible humour and spunk. Relationships with residents marked me (Das, 2007). The impact reverberated across my relationships with family and friends – revealing new depths in some, surprises in others, and healing one long-term rupture. Seeing how inequities stunted human potential, how convictions of 'good' overlooked its harms, and how our lives interconnected was a bone I could not let go of. Anyone who asked heard about it. Some turned away. It was my intensity one friend explained: What were good people to do – take the homeless home? Another found my critique of health care disturbing: Was her entire career as a nurse for naught? In the course of completing the study, technology and neoliberal reforms have continued and, if anything, accelerated making the humanity in care increasingly precious and precarious, in some ways, while more fully acknowledging it (in policy at least) in services for those marginalized by addictions and poverty.

My regard for residents was not unique: The commitment of numerous providers was also a response to residents' brilliance and, at times, a testament to love. Many of the residents who contributed to this study have passed on since I conducted fieldwork. Thinking of them reminds me of their vitality, generosity, and courage. In honor of all

who helped, and in acknowledgment of the unceded territory of Coast Salish peoples where this study was conducted, I conclude with the words of a Salish Elder:

One motto of our ancestors was love and kindness to everybody. Don't mistreat anybody, don't criticize anybody. . . . Before contact, our ancestors were communicating with the animals. They communicated with the feathered friend, the four-legged friend, the sea creatures . . . the bear and all the other animals. . . . And then we lost it. When we were trying to show who was powerful, the bear shows his power, the hummingbird shows his power, the eagle, the raven, the deer would dance, and the fish, the whale – *oh that great big humungous whale would jump and dance on top of the water* – and all the other sea creatures. They were showing their power learning to live together. And then they turned to this human and said 'What power do you have?' And he pulled out his quiver and arrow, drew it and he looked at the biggest animal that was close and let his arrow fly. It hit the grizzly bear right in the heart and it died. And the animals looked at the human and said, 'That's not power'. So all the animals turned and walked away, and that's how we lost communication with the animal world. [*So what is power?*] Power is the flight of the hummingbird, the flight of the eagle, the flight of the crow. Power is the sea creatures going under water. Power is the bear catching the salmon and feeding his family and the wolf taking care of the family. Those are powers. The power we have, we have a hard time bringing out: the love and the kindness. That's the strongest power, love and kindness (Interview, 2 July 2010, 30 July 2010).

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## Appendix A.

# Letter of Agreement to Conduct Research at Vancouver Native Health Society (VNHS)

**Project Title:** Two worlds, one hope? A multi-sited ethnography of how biomedical discourses of antiretroviral drugs interact in two settings to influence marginalized peoples' access to and use of drugs.

**Primary Researcher:** Lesley Cerny, PhD Candidate, Department of Sociology and Anthropology, Simon Fraser University.

**Research Supervisor:** Dr. Dara Culhane, Department of Sociology and Anthropology, Simon Fraser University.

For purposes of this study involvement of VNHS includes professional health care staff, peers, support staff and volunteers of the Positive Outlook Program (POP), Vancouver Native Health Clinic (VNHC), and the study "Complete Health Care for Native Urban People Self-Management Program (CHCNU-PSMP). Principle site contacts for this research are Dr. David Tu (Medical Director, VNHC) and Doreen Littlejohn (Coordinator, POP).

**Background:** This letter of agreement between Lesley Cerny and VNHS is being undertaken for the purpose of research to fulfill requirements for a PhD at Simon Fraser University, Department of Sociology and Anthropology. Overall, the study aims to broaden understanding of the factors that influence marginalized peoples' access to and use of antiretroviral drugs (ART) in Canada and in a low-income country by:

- a) Examining the similarities and differences in how biomedical knowledge of ARTs is understood by providers and marginalized patients.
- b) Examining how differences in histories of colonialism, contemporary processes of inequality, and the epidemiology of HIV influence providers' and marginalized peoples' experiences, understandings and responses to ART.

The researcher and VNHS are committed to conducting research that is informed by the Royal Commission on Aboriginal Peoples' Ethical Guidelines for Research and the CIHR Guidelines for Health Research Involving Aboriginal peoples. Guidance for this project will be provided through ongoing consultations with the VNHS site contacts, staff, elder and marginalized peoples living with HIV.

**Timeline:** This letter of agreement is intended to apply throughout the length of the CIHR funded study (2007-2012) and for 10 years beyond to allow time for the knowledge translation activities that are to follow. The primary researcher also acknowledges this Letter of Agreement is a dynamic document to be modified based on our mutually reciprocal research partnership.

**Guiding Principles:** The research will be conducted with respect for the diverse backgrounds and interests of VNHS staff, volunteers and clients/patients by:

- Involving Aboriginal and non-Aboriginal peoples' (VNHS providers and clientele) in the design, implementation, analysis and translation of results.
- Being responsive to Aboriginal and non-Aboriginal peoples' (VNHS providers and clientele) input throughout the project to ensure research activities "fit" the organizational context and participants'

interests, concerns and needs.

**Participation:** Participation of VNHS patients and providers is voluntary. Written consent to conduct participant observation of VNHS staff, peers and volunteers will be obtained at the outset of the study. The written consent form for VNHS staff and peers also encompasses their participation in interviews and focus groups. However, prior to observing patient/provider encounters or conducting interviews, staff/peers' and patients' verbal consent to participate will be confirmed. The researcher will follow VNHS protocols for informing clientele in POP and VNHC of the study, and for observing patient / provider interactions. Written consent will be obtained prior to conducting any interviews, focus groups or other research activities with patients/clients.

**Confidentiality:** As outlined in the SFU Ethics Review process and consent forms for VNHS staff, peers, volunteers and clients, all confidential information will be held in strictest confidence by the researcher. Participants' names will be changed through the assignment of pseudonyms or code-numbers. Confidential patient records will be reviewed in a private location at VNHS. No copies of clinical charts or its components will be made. The researcher will make notes, but no personal, identifying information will be recorded. Copies of selected responses on CHCNUP surveys or patient goal sheets will only be made with the prior consent of Dr. Tu and Doreen Littlejohn. Any identifying information will be removed from copies of these documents. Research materials such as notes, audio records, interview transcripts or copies of documents from the CHCNUP study will be kept in a locked filing cabinet in the offices of Lesley Cerny for a period of ten years before disposal and will not be publically accessible. All computer files will be password protected. No names will be included in articles, reports, or presentations unless by prior agreement of participants.

**Research Activities and Responsibilities:** The research methodology is detailed in the PhD Prospectus shared with VNHS site contacts. In exchange for being able to conduct the PhD research at VNHS, Lesley Cerny agrees to conduct an ethnographic evaluation of the CHCNUP study at no cost to VNHS. As part of this, Lesley Cerny agrees to:

- Actively participate in meetings among the Research Team, selected meetings of peer-coaches and VNHS staff throughout the study.
- Conduct interviews with 21 patients enrolled in CHCNUP, per the methodology outlined in the CHCNUP proposal. Interview data will be provided to VNHS on completion of the evaluation report.
- Bear all costs for participant recruitment and interviews of patients, and a maximum of 5 focus groups among peer coaches involved in the CHCNUP study.
- Provide a written evaluation of the CHCNUP study to VNHS within 4 months following completion of the CHCNUP study.

In exchange, VNHS agrees that Lesley Cerny will:

- Conduct participant observation of POP, VNHC, and the CHCNUP study. This includes observing everyday interactions at VNHS, attending meetings, and observing patient/provider interactions.
- Approach staff and patients for participation in interviews throughout the study. VNHS supports staff in providing interviews on work-time. Lesley Cerny will bear all costs for recruiting and interviewing patients and peers, and for refreshments provided during interviews and focus groups.
- Provide access to clinical records, CHCNUP surveys and patient goal sheets for selected clientele.

**Research data:** Lesley Cerny will maintain sole ownership of all notes collected during this project. Given the need to maintain confidentiality, all participants will be offered the opportunity to review interview transcripts, upon request, within two months of the interview. Professional providers will be provided with copies of interview transcripts upon request. Any professional providers who participate in regular interviews will be automatically provided with interview transcripts to ensure accuracy and agreement on content. VNHS maintains ownership of all VNHC health records, CHCNUP surveys and related patient records.

**Roles:** To promote clarity in Lesley Cerny's dual research roles, and between her role as researcher and status as registered nurse, the researcher will refrain from providing clinical assistance or interventions, taking minutes of meetings that may later be included as documentary data, or assuming any role that could be perceived by peers as supervisory. Additional strategies for maintaining clarity between these roles, developed with input from VNHS site contacts, is attached.

**Research publications:** Principles of cooperation, respect and recognition will inform translation of research results. Lesley Cerny is amenable to joint-publications and presentations based on research results. VNHS reserves the right to determine whether or how their involvement is acknowledged in all publications and presentations based on PhD research. Draft publications will be shared with Dr. Tu and Doreen Littlejohn prior to submission for publication or presentation. In the event of a disagreement in analysis or representation of findings, Lesley Cerny will engage in a conflict resolution process such as: including dissenting opinion(s) and / or removing the identity of the institution. Lesley Cerny will participate as co-author and / or be acknowledged in any publications based on the ethnographic data and / or evaluation of the CHCNUP study.

**Benefits:** Lesley Cerny is committed to applying research findings in ways that are beneficial to Aboriginal and non-Aboriginal people marginalized as a result of social, historical and economic circumstances, and to Aboriginal and non-Aboriginal people who provide health services to marginalized clientele. The study is expected to contribute knowledge that can be used to strengthen VNHS services for Aboriginal and non-Aboriginal peoples living with HIV.

**Commencement of Research:** Approval to conduct research at VNHS is contingent on receiving confirmation of ethical approval from SFU and approval of an application to conduct research at VNHS.

**Funding:** The project is funded by a Fellowship from Canadian Institute of Health Research HIV/AIDS Research Initiative.

Signed by:

Date

Signature of Researcher

Signature of Agency Contact(s)

Name

Name

Position:

Position

### **Strategies for Keeping Research Roles Distinct with the VNHS and PhD Studies**

#### **Methodological**

- VNHS study does not address the lived experiences of providers. Therefore, any and all interviews with providers will be considered part of my PhD research.
- VNHS study only considers general patterns in the nature / content and practices of each group of providers. Individual practices will only be identified or discussed with the explicit verbal consent of the individual involved.
- Peers have been consulted in the design of the ethnographic evaluation and the content of survey questions. Any concerns regarding approaches or questions will be addressed to the satisfaction of peers throughout the study. I will independently consult a peer(s) to identify additional strategies for ensuring my roles are clearly differentiated.
- In consultation with peers, I will develop a process for peers to express concerns about my roles with the VNHS study / PhD research.

- Peers have been informed of the difference between “program evaluation” and “performance evaluation”. I will continue to reinforce this throughout the study.
- Verbal consent will be requested from peers before observing any encounter. Individuals who decline or provide consent will not be identified. An effort will be made to distribute observations among consenting peers.
- Bi-monthly interviews which link VNHS and PhD interests:
  - Responses for VNHS study will be written on a colour-coded paper.
  - Participation in these interviews excludes peers involved with the VNHS study.
  - Pending participants’ preferences and consent, I will seek to conduct interviews for both studies off-site.
- Data to track implementation of the VNHS study will be drawn from group interactions and participant observation. Notes regarding implementation of the VNHS study will be periodically reviewed with peers who will have an opportunity to comment prior to having results shared with the VNHS study research team.
- Interviews for my PhD research will be conducted in varied social settings and activities.
- Preliminary findings with my PhD research will be reviewed with peers/ marginalized people before results are shared and discussed with providers.
- A consistent approach for honorariums will be used in both studies.

#### **Practical**

- I will decline requests to provide direct support to peers in their roles with the VNHS study. I will direct all peers who express concerns with the design or administration of the VNHS study to discuss these directly with VNHS study Coordinator.
- I will not engage in discussion of individual peers practices among the Research Team.
- I will strictly adhere to the focus of the VNHS study questions. Any illicit or unethical practices observed among providers or between providers and patients will not be reported or discussed.
- Ethical dilemmas arising from the potential blurring of my roles will be reviewed and discussed with my supervisor.

#### **Between Role as Researcher and Status as Registered Nurse**

- I will not participate in the provision of clinical skills or in providing input on clinical matters. In the event of being called to assist in an emergency, I would assume roles consistent with my current level of clinical competence: such as calling for emergency assistance or managing bystanders. A bilateral wrist injury prevents me from updating my Basic CPR Certification at this time.
- To address ethical dilemmas arising from these dual roles, I have provisionally set up a committee comprised of a Practice Consultant at the College of Registered Nurses of BC and my supervisor.

# Appendix B.

## Participant Consent Forms

### Consent for VNHS staff

**PhD Research Project:** “Two worlds, one hope?” A multi-sited ethnography of how biomedical discourses of antiretroviral drugs interact in two settings to influence patients’ access to and use of drugs.

**Principal investigator:** Lesley Cerny, PhD Candidate, Department of Sociology and Anthropology, Simon Fraser University. The study is supervised by Dr. Dara Culhane, Department of Sociology and Anthropology, SFU. *The study is funded by a Canadian Institute of Health Research HIV/AIDS Research Fellowship.*

**The purpose of the study** is to provide new insight into the factors that influence marginalized patients’ use of antiretroviral drugs (ART). The study aims to do this by comparing providers and marginalized patients’ understandings of and responses to ARTs in Canada and in a low-income country. The study examines:

- how health providers and patients understand ARTs
- how these understandings influence providers and patients’ responses to HIV/ART
- how histories of colonialism and conditions of social inequality affect ART provision and use
- how the practices of providers help or hinder patients’ access to or use of ART.

The study is expected to provide information that will help VNHS strengthen existing services for people living with HIV and those using ARTs.

**Participation is voluntary** and you can withdraw at any time without any negative effect to your employment at VNHS. You can refuse to answer questions, refuse to be observed and refuse to be interviewed. You can stop participating at any time and no questions will be asked. If you worry that information collected during research may identify you, you can ask to have it withdrawn.

**Information is being collected** from: 1) Observations, 2) interviews, 3) focus groups, 4) documentary sources, 5) ad-hoc consultations and 6) walking tours.

**Observations:** To gain a better understanding of what its like to live with HIV and provide HIV/ART services, I will observe staff meetings, informal interactions between staff and patients in POP, the clinic, and the CHCNUP study. Observation of everyday interactions will be ongoing throughout fieldwork. I may ask to accompany you for part of a shift as you provide care to patients. In this case I will be observing things such as verbal and non-verbal communication and the types of concerns discussed in interactions. Observation of clinical interactions is planned to occur between the 3<sup>rd</sup> and 9<sup>th</sup> month of fieldwork. During this period, I will rotate between observing physicians, nurses, and peers. I do not expect to spend more than 2 days per week observing patient care in all settings combined. These observations will not require any additional time from you. Beforehand, I will ask your advice on ways to ensure observation is not disruptive. I will also confirm your verbal consent by asking:

*“I would like to observe your interactions with patients on (day). Are you OK with this? Feel free to say no if you have any hesitation. The patient must also consent before I observe”.*

I will make brief notes for recall purposes. Fieldnotes are for my exclusive use. However, I will periodically extract *general* information from fieldnotes for use with my independent role evaluating the CHCNUP study (as outlined in the consent for the CHCNUP study). This general information will not identify individuals.

**Interviews:** You may be invited to participate in an interview(s) during the year. Interviews will be oriented to understanding one of the following: 1) details of past or present HIV/ART services at VNHS and in the Downtown Eastside, 2) your general experiences in providing HIV/ART services, 3) your experiences of a specific clinical encounter. I will confirm your verbal consent when requesting the interview. All interviews will last between 30-60 minutes and occur at a time and place convenient for you. With your permission, interviews will be recorded. You can request to review the interview transcript and / or obtain a copy of it within two months of the interview. Staff involved in serial interviews will automatically be provided with copies of interview transcripts to ensure accuracy and agreement on content.

If you and the patient consent to be interviewed following clinical encounters, you understand that I will review the patients' health records pertaining to this interaction. My examination of clinical records will focus on: pertinent laboratory indicators of HIV infection (such as CD4 count and viral load); clinical notes and interventions; documentation regarding ART use or non-use; and specialist reports. I may also review patients' survey responses and personal goal sheets from their participation in the CHCNUP study. Personal health records will never leave the premises of VNHS and will only be reviewed in a private area of VNHS. Notes taken from clinical records will not include any personal identifiers. Copies of patients' survey responses and personal action plans will have all personal identifiers removed.

**Documentary evidence:** Signing this form indicates your awareness that I may review VNHS policies and procedures related to HIV/ART care and health records of selected patients (pending patient's consent) as noted above.

**Ad-hoc consultation:** To reflect the collaborative nature of this study, I will periodically seek staff input on project methods, substantive areas of concern, and analysis.

**Focus groups:** You will be invited to participate in a focus-group discussion and analysis of preliminary findings of the study. This will occur before any findings are reported in the PhD dissertation, or included in other articles or presentations of this research.

Quotes gathered from interviews and focus groups may be used in research reports or other publications, but anything that might identify you will be removed or changed.

**Risks and Benefits:** There are no known physical risks for participating in this study. Providers may be concerned that I am evaluating their clinical knowledge or practices with respect to HIV/ART care. I am not evaluating your knowledge or practice. Rather, I am interested in eliciting your perspectives, experiences and priorities in providing HIV/ART care. The information you provide will not affect your employment at VNHS in any way. Your participation will help determine how providers understand and apply the science of ARTs to "fit" the realities and needs of people living with HIV in Vancouver's Downtown Eastside.

**Confidentiality:** The information you provide will be held in the strictest confidence. Your identity will not be released without your consent except if required by law or regulation. Your confidentiality will be protected in several ways:

- Your name will not be used in the study or in any reports or articles written about the study. Instead, a number code or pseudonym will be given to each person.
- Information collected during observation of POP, clinic and CHCNUP activities will be held in the strictest confidence.

- Nurses, doctors, and other staff at VNHS will not be able to see, read, or hear any of the information you provide in a way that will identify you.
- Your employers or supervisor will not have access to any of the information you provide. The only people who will see the research information will be the researcher and her supervisor who is also required to keep all information in strict confidence.
- All information will be securely stored in a locked cabinet in the researchers' office or stored in a password protected computer file.
- If you worry that information collected during research may identify you, you can ask to have it withdrawn.

In accordance with the [CIHR Guidelines for Health Research Involving Aboriginal People](#), VNHS reserves the right to determine whether or how their participation in the project is acknowledged in research reports, articles or presentations.

**Limits of this consent:** The study involves two field sites. This consent form pertains to fieldwork at the first site. Once details for the second site are confirmed, participants at the first site will be invited to sign another consent for their participation in any dialogue and / or analysis that involves participants or field data from the second site.

**Data ownership:** While Lesley Cerny maintains sole ownership of all data collected for this study, the cooperative nature of this research is recognized in several ways. Providers will have an opportunity to review and discuss preliminary data before findings are presented in the PhD dissertation. Draft copies of reports, articles and presentations will be reviewed with VNHS contacts, Dr. David Tu and Doreen Littlejohn, a minimum of 2 weeks before being submitted for publication or presentation. I am also open to exploring the possibility of joint authorship on publications. If there are disagreements in analysis between the researcher and participants/VNHS, appropriate conflict resolution strategies will be employed, such as including objections in articles.

Results of this study will be presented in reports and articles, and presented at health care meetings and conferences. The researcher may use this research in future analysis, but all research information will be destroyed after 10 years. A copy of research results will be made available to staff and patients at VNHS. Additional copies can be obtained by contacting Lesley Cerny, PhD Candidate c/o Department of Sociology and Anthropology, Simon Fraser University.

This study has been approved by Lou Demerais, Executive Director, VNHS. No other Aboriginal organizations or Band Councils were consulted for approval. Your honest feedback is welcomed and encouraged. Any concerns or complaints about the study can be directed to Dr. David Tu or Doreen Littlejohn at VNHS, or to Dr. Hal Weinberg, Director, Office of Research.

**Consent:** You do not waive any of your legal rights by signing this consent form. A copy of this consent form will be given to you for your own records. For questions about this study please contact Lesley Cerny. By signing this consent form you agree to participation in the study described above.

_____	_____
Signature of Participant	Date
_____	_____
Please Print Your Name	Contact Phone Number
_____	_____
Present Staff Position	Contact Email Address

## Consent for VNHS peers

**PhD Research Project:** “Two worlds, one hope?” A multi-sited ethnography of how biomedical discourses of antiretroviral drugs interact in two contexts to influence patients’ access to and use of drugs.

**Principal investigator:** Lesley Cerny, PhD Candidate, Department of Sociology and Anthropology, Simon Fraser University. The study is supervised by Dr. Dara Culhane, Department of Sociology and Anthropology, SFU. *The study is funded by a Canadian Institute of Health Research HIV/AIDS Research Fellowship.*

**The purpose of the study** is to provide new insight into the factors that influence peoples’ use of ART. The study aims to do this by comparing providers and patients’ understandings of and responses to ARTs in Canada and in a poor country. The study examines:

- how health providers and patients understand ARTs
- how these understandings influence providers’ and patients’ responses to HIV/ART
- how histories of colonialism and social conditions affect ART provision and use.
- how the practices of providers help or hinder peoples’ access to or use of ART.

The study is expected to provide information that will help VNHS strengthen existing services for people living with HIV and those using ARTs.

**Participation is voluntary** and you can withdraw at any time without any negative effect to your volunteer or paid employment or the health care you receive at VNHS. You can refuse to answer questions, refuse to be observed and refuse to be interviewed. You can stop participating at any time. No questions will be asked. If you worry that information collected during research may identify you, you can ask to have it withdrawn.

**Information is being collected** from: 1) Observations, 2) interviews, 3) focus groups, 4) documentary sources, 5) ad-hoc consultations and 6) focus groups.

Observations: To gain a better understanding of what it’s like to live with HIV and provide HIV/ART services, I will observe staff meetings, informal interactions between staff and patients in POP, the clinic, and the CHCNUP study. Observation of everyday interactions will be ongoing throughout fieldwork. I may also ask to accompany you for part of a shift as you provide care to patients. In this case I will be observing things such as verbal and non-verbal communication and the types of concerns discussed in interactions. Observation of clinical interactions is planned to occur between the 3<sup>rd</sup> and 9<sup>th</sup> month of fieldwork. During this period, I will rotate between observing physicians, nurses, and peers. I do not expect to spend more than 2 days per week observing patient care in all settings combined. These observations will not require any additional time from you. Beforehand, I will confirm your verbal consent by asking:

*“I would like to observe your interactions with a patient. Are you OK with this? Feel free to say no if you have any hesitation. The patient must also consent before I observe.”*

If you consent, I will ask your advice on the best way to introduce myself to the patient and ways to ensure that my observation is not disruptive for either of you.

I will make brief notes for recall purposes. Field notes are for my use only. However, I will periodically summarize information from my field notes for use with my separate role in the CHCNUP evaluation (outlined in the consent for the CHNUP study). This general information will not identify individuals.

Interviews: You may be invited to participate in an interview(s) during the year. Interviews will be oriented to understanding one of the following: 1) details of past or present HIV/ART services at VNHS

and / or the Downtown Eastside, 2) your general experiences in providing HIV/ART services, 3) your experiences of a specific clinical encounter. I will confirm your verbal consent when requesting the interview. All interviews will last between 30-60 minutes and occur at a time and place convenient for you. With your permission, interviews will be recorded. You can request to review the interview transcript within two months of the interview.

If you and the patient consent to be interviewed following clinical encounters, you are agreeing that I may review the patients' health records pertaining to this interaction. My examination of clinical records for the observed interaction will focus on: pertinent laboratory indicators of HIV infection (such as CD4 count and viral load); clinical notes, concerns, and interventions; documentation regarding ART use or non-use; specialist reports. I may also review patients' survey responses and personal action plans from their participation in the CHCNUP study. Personal health records will never leave the premises of VNHS and will only be reviewed in a private area of VNHS. Notes taken from clinical records will not include any personal identifiers. Copies of patients' survey responses and goal sheets will have all personal identifiers removed

Documentary evidence: Signing this form indicates your awareness that I may review VNHS policies and procedures related to providing HIV/ART care and access health records of patients (pending patient's consent) as outlined above.

Ad-hoc consultation: To reflect the collaborative nature of this study, I will periodically seek staff input on project methods or substantive areas of concern, and analysis.

Focus groups: You will be invited to participate in a focus-group discussion of preliminary findings of the study. This will occur before any findings are reported in the PhD dissertation, or included in other articles or presentations of this research.

Quotes gathered from interviews and focus groups may be used in research reports or other publications, but anything that might identify you will be removed or changed.

**Risks and Benefits:** There are no known physical risks for participating in this study. Some peers may feel concerned that being observed could affect their employment and broader relationships with VNHS. The information will not be used to evaluate your work or the work of your colleagues in any way. Rather, the information will be used to examine broader issues related to ART access and use. Your identity will not be released without your consent unless required by law or regulation.

To ensure the study does not negatively impact your work and broader relationships with VNHS, you will have an opportunity to review preliminary findings before they are shared with VNHS staff. Your participation will help determine how providers understand and apply the science of ARTs to "fit" the realities and needs of people living with HIV in Vancouver's Downtown Eastside.

**Confidentiality:** The information you provide will be held in the strictest confidence. Your confidentiality and that of your patients will be protected in several ways:

- Your name will not be used in the study or in any reports or articles written about the study. Instead, a number code or pseudonym will be given to each person.
- Information collected during observation of POP, clinic and CHCNUP activities will be held in the strictest confidence.
- Nurses, doctors, and other staff at VNHS will not be able to see, read, or hear any of the information you provide in a way that will identify you.
- Your employers or supervisor will not have access to any of the information you provide. The only people who will see the research information will be the researcher and her supervisor who is also required to keep all information in strict confidence.
- All information will be securely stored in a locked cabinet in the researchers' office or stored in a password protected computer file.

- If you worry that information collected during research may identify you, you can ask to have it withdrawn.

In accordance with the [CIHR Guidelines for Health Research Involving Aboriginal People](#), VNHS reserves the right to determine whether or how their participation in the project is acknowledged in research reports, articles or presentations.

**Limits of this consent:** The study involves participants at two locations. This consent form pertains to your involvement at the first site. Once details for the second location are confirmed you may be invited to sign another consent for participation in any discussions or activities that include people at the second site.

**Data ownership:** While Lesley Cerny has sole ownership of all data collected for this study, the cooperative nature of this research is recognized in several ways. Peers will have an opportunity to review and discuss preliminary data before findings are discussed with VNHS staff and presented in the PhD dissertation. Draft copies of reports, articles and presentations will be reviewed with VNHS contacts, Dr. David Tu and Doreen Littlejohn, before being submitted for publication or presentation. VNHS retains the right to decide whether or how VNHS’s participation in this study is acknowledged. If there are disagreements in analysis between the researcher and participants/VNHS, appropriate conflict resolution strategies will be employed, such as including objections in articles.

Results of this study will be presented in reports and articles, and presented at health care meetings and conferences. The researcher may use this research in future analysis, but all research information will be destroyed after 10 years. A copy of research results will be made available to staff and patients at VNHS. Additional copies can be obtained by contacting Lesley Cerny, PhD Candidate c/o Department of Sociology and Anthropology, Simon Fraser University.

This study has been approved by Lou Demerais, Executive Director, VNHS. No other Aboriginal organizations or Band Councils were consulted for approval. Your honest feedback is welcomed and encouraged. Any concerns or complaints about the study can be directed to Dr. David Tu or Doreen Littlejohn at VNHS, or to Dr. Hal Weinberg, Director, Office of Research.

**Consent:** You do not waive any of your legal rights by signing this consent form. A copy of this consent form will be given to you for your own records. If you prefer, Lesley Cerny may keep your copy of the consent form in a locked file until you request it. Any consent forms left in Lesley’s care will be destroyed 5 years after completion of the study. For questions about this study please contact Lesley Cerny. By signing this consent form you agree to participation in the study described above.

I have requested that Lesley Cerny keep my copy of this consent form in a secure, locked cabinet until I request it. Yes  No

Signature of Participant

Date

\_\_\_\_\_

\_\_\_\_\_

Please Print Your Name

Contact Phone Number

\_\_\_\_\_

Contact Email Address

## Consent for bi-monthly interviews

**PhD Research Project:** “Two worlds, one hope?” A multi-sited ethnography of how biomedical discourses of antiretroviral drugs interact in two contexts to influence patients’ access to and use of drugs.

**Principal Investigator:** Lesley Cerny, PhD Candidate, Department of Sociology and Anthropology, Simon Fraser University. The study is supervised by Dr. Dara Culhane, Department of Sociology and Anthropology, SFU.

*The study is funded by a Canadian Institute of Health Research HIV/AIDS Research Fellowship.*

**The purpose of the study** is to provide new information about things that affect peoples’ use of antiretroviral drugs (ARTs) The study will compare providers and patients’ understanding and response to ARTs in Canada and a poor country. The study examines:

- how health providers and patients understand ARTs
- how these understandings influence providers and patients’ responses to HIV/ART
- how histories of colonialism and conditions of social inequality affect ART provision and use
- how the practices of providers help or hinder patients’ access to or use of ART.

Results of the study will help VNHS give better health care to people living with HIV and to those who take ARTs.

**Participation is voluntary** and you can withdraw at any time without any effect on the health care or services you receive at POP or the Clinic. You can refuse to answer questions and you can stop participating at any time. No questions will be asked. If you worry that information collected during research may identify you, you can ask to have it withdrawn.

**Information for the study** is being collected from: 1) interviews, 2) hanging out together, 3) written documents, 4) consultations, and 5) group discussions

I am inviting you to participate in this project. I am interested in understanding your life and experiences living with HIV. If you agree to participate, it would include the following:

**Interviews:** Participating in an interview every two months from June 2009 to April 2010. These will last from 30 minutes to 2 hours, at a convenient time and in a place that is comfortable for you. This could be at VNHS or outside VNHS. If you agree, I will combine interviews with activities that will give me a broader understanding of your life, like walking tours of the Downtown Eastside. If you agree, I will record some interviews. You can ask to see and discuss interview transcripts up to 2 months after the interview.

**Hanging out together:** If you agree, I might join you on a visit to a doctor. The purpose would be to understand your experience of health services. If I attend a doctors’ visit with you, I will observe the interaction. I will only speak if you ask me to and you can ask me to leave at any time. I might also ask to hang-out with you for all or part of a day to help me understand what life is like in the Downtown Eastside. If we hang out for awhile, I do not want you to do anything “special”. You can ask me to leave at any time.

I will make brief notes about the time we spend together for recall purposes. Field notes are for my use only. You will receive an honorarium of \$15 per hour for each interview or the other time we spend hanging out together.

**Survey responses and goal sheets for the other study (CHCNUP):** To get a better understanding of your experience, information from our interviews will be linked with your information from the CHCNUP study and your other health records at VNHS. If you decide to participate, I will review your survey responses

and personal action plans for the CHNUP study, and your other health records at VNHS. I am only interested in survey responses that relate to ART. I am not looking at whether survey answers are “right” from a doctors’ perspective, or in changing what you are doing (or not doing) with ARTs. I am also not interested in what you are doing (or not doing) about your action plans in the CHCNUP study. Rather, I am interested in how *you* understand medical information, how *you* understand visits with health providers (ie: what helps, what doesn’t and why), and what *you* see as important to your life and health.

Looking at your medical records will help me understand how changes in your life are connected to changes in your health. I am also interested in how providers understand your health and whether this is the same or different to your views. My review of your health records will look at laboratory records of your health, providers’ notes of your visits, what they see as main problem and how they treat it, your ART medications and any notes related to this, and letters from specialists. I will make brief notes from your records for recall purposes, but no information that can identify you will be recorded. Your medical records will never leave VNHS and will only be reviewed in a private area of the clinic. If you have any questions about your records, I will ask you to talk to your health provider.

To assist with analysis you will be invited to discuss early results of the study in a small group. Quotes gathered from interviews and focus groups may be used in research reports or other publications, but anything that might identify you will be removed or changed.

**Signing this consent** means you agree to:

- Let me contact you for an interview every two months from June 2009 until April 2010.
- Let me look at your survey responses and goal sheets for the CHCNUP study and include them in my research.
- Let me look at your health records at Vancouver Native Health clinic and POP, take notes and include these notes in my research.
- Let me invite you to a group discussion of preliminary findings at the end of the study.

**Risks and Benefits:** There are no known physical risks for participating in this study. You may be concerned that information you share with me in interviews will be reported to your provider. Your identity will not be released without your consent unless required by law or other regulations. Your participation in the study will provide information to help improve health services for people living with HIV in the Downtown Eastside.

**Confidentiality:** The information you provide will be held in the strictest confidence. Doreen Littlejohn at POP introduced me to people that might be interested in being involved in this study. However, Doreen will not know if you consent to participate or anything else we discuss or do together.

Your confidentiality will be protected in several ways:

- Your name will not be used in the study or in any reports or articles written about the study. Instead, a number code or pseudonym will be given to each person.
- Information collected during observation of your activities and interactions will be held in the strictest confidence.
- Nurses, doctors, and other staff at VNHS will not be able to see, read, or hear any of the information you provide in a way that will identify you.
- The only people who will see the research information will be the researcher and her supervisor who is also required to keep all information in strict confidence.
- All information will be securely stored in a locked cabinet in the researchers’ office or stored in a password protected computer file.
- If you worry that information collected during research may identify you, you can ask to have it withdrawn.

VNHS reserves the right to decide whether or how its participation in this study is acknowledged.

**Limits of this consent:** The study involves participants at two locations. This consent form pertains to your involvement at the first site. Once details for the second location are confirmed you may be invited to sign another consent for participation in any discussions or activities that include people at the second site.

**Data ownership:** Lesley Cerny maintains sole ownership of all data collected for this study but the cooperative nature of this research is recognized in several ways. Participants will have an opportunity to discuss early results before these are shared with VNHS staff and presented in the PhD dissertation. Copies of reports, articles and presentations will be reviewed with VNHS contacts, Dr. David Tu and Doreen Littlejohn, before being submitted for publication or presentation. If there are disagreements in analysis between the researcher and participants/VNHS, appropriate conflict resolution strategies will be employed, such as including objections in articles. Results of this study will be presented in reports and articles, and presented at health care meetings and conferences. The researcher may use this research in future analysis, but all research information will be destroyed after 10 years.

A copy of research results will be made available to you through VNHS. Additional copies can be obtained by contacting Lesley Cerny, PhD Candidate c/o Department of Sociology and Anthropology, Simon Fraser University.

This study has been approved by Lou Demerais, Executive Director, VNHS. No other Aboriginal organizations or Band Councils were consulted for approval. Your honest feedback is welcomed and encouraged. Any concerns or complaints about the study can be directed to Dr. David Tu or Doreen Littlejohn at VNHS, or to Dr. Hal Weinberg, Director, Office of Research.

**Consent:** You do not give up any of your legal rights by signing this consent form. A copy of this consent form will be given to you for your own records. If you prefer, Lesley Cerny may keep your copy of the consent form in a locked file until you request it. Any consent forms left in Lesley's care will be destroyed 5 years after completion of the study. For questions about this study please contact Lesley Cerny. By signing this consent form you agree to participation in the study described above.

I have requested that Lesley Cerny keep my copy of this consent form in a secure, locked cabinet until I request it. Yes  No

Signature of Participant

Date

\_\_\_\_\_

Please Print Your Name

\_\_\_\_\_

Best Way to Contact (email, phone, other)

# Consent for VNHS volunteers general participation and patients' participation in ad-hoc interviews and other activities

**PhD Research Project:** "Two worlds, one hope?" A multi-sited ethnography of how biomedical discourses of antiretroviral drugs interact in two contexts to influence patients' access to and use of drugs.

**Principal investigator:** Lesley Cerny, PhD Candidate, Department of Sociology and Anthropology, Simon Fraser University. The study is supervised by Dr. Dara Culhane, Department of Sociology and Anthropology, SFU. *The study is funded by a Canadian Institute of Health Research HIV/AIDS Research Fellowship.*

**The purpose of the study** is to get new information about factors that influence peoples' use of antiretroviral drugs (ARTs). The study will do this by comparing providers and patients' understanding and response to ARTs in Canada and in a poor country. The study examines:

- how health providers and patients understand ARTs
- how these understandings influence providers' and patients' responses to HIV/ART
- how histories of colonialism and conditions of social inequality affect ART provision and use
- how the practices of providers help or hinder patients' access to or use of ART.

Results will help providers provide better health care to people living with HIV and to those who take ARTs.

**Participation is voluntary** and you can withdraw at any time without any negative effect to your volunteer or paid employment or the health care you receive at VNHS. You can refuse to answer questions, refuse to be observed and refuse to be interviewed. You can stop participating at any time. No questions will be asked. If you worry that information collected during research may identify you, you can ask to have it withdrawn.

**Information for the study is being collected** from: 1) Observations, 2) interviews, 3) written documents, 4) consultations, and 5) group discussions.

Observations: To better understand what its like to live with HIV and provide HIV and ART services, I will observe staff meetings, everyday interactions between staff and members/patients in POP, the clinic, and the CHCNUP study. Observation of everyday interactions will be ongoing throughout the year of fieldwork. If you agree, I may accompany you on a visit to a doctor. The purpose would be to understand your experience of health services. If I attend a doctors' visit, I will observe the interaction and only speak if you ask me to. You can ask me to leave at any time. I might also ask to hang-out with you for all or part of a day to help me understand what life is like in the Downtown Eastside. If we hang out for awhile, I do not want you to do anything "special". You can ask me to leave at any time.

I will make brief notes for recall purposes. Field notes are for my use only. However, I will periodically summarize information from observation at VNHS for use with my separate role in the CHCNUP evaluation (outlined in the consent for the CHCNUP study). This general information will not identify individuals. No other information collected from observations will be shared.

Interviews: You may be invited to participate in an interview. Interviews will focus on either: 1) your knowledge of past or present HIV/ART services, 2) your experiences with HIV and or ART, 3) your perspective on specific issues like drug use. All interviews will last between 30-60 minutes and occur at a convenient time and in a place where you feel comfortable. With your permission, interviews will be recorded. You can request to review the interview transcript within two months of the interview.

Written documents: You might be invited to write stories about life and the experience of living in the Downtown Eastside. These stories will be included with other information collected in the study and may be quoted in written reports or articles. Consent to provide written material for this study means that you agree to release your “copyright” or any claims of ownership to this writing to the researcher.

Consultation: You might be invited to give advice on things like survey questions.

Group discussions: All participants will be invited to participate in a group discussion of early results of the study. This will occur before results are reported in the PhD dissertation, or included in any other articles or presentations of this research. If you sign this consent, you agree that I may contact you later and invite you to participate in a focus group.

Quotes gathered from interviews, group discussions or stories you write may be used in research reports or other publications, but anything that might identify you will be removed or changed.

Signing this consent means you agree to participate in (*to be checked by the researcher*):

- my observation of everyday activities in VNHS
- my observation of your doctors’ visit
- hanging out together for all or part of a day
- an interview
- providing written documents
- providing consultation
- letting me contact you later about participation in a group discussion.

**Risks and Benefits:** There are no known physical risks for participating in this study. Volunteers at POP may be worried that being observed could affect their work or broader relationships with VNHS. The information will not be used to evaluate your work or the work of your colleagues in any way. Rather, the information will be used to examine broader issues related to ART access and use. To ensure the study does not negatively impact your work and relationships with VNHS, you will have an opportunity to review preliminary findings before they are shared with VNHS staff. Your identity will not be released without your consent unless required by law or regulations. Your participation in the study will provide information to help improve health services for people living with HIV in the Downtown Eastside.

**Confidentiality:** The information you provide will be held in the strictest confidence. Your confidentiality and that of your patients will be protected in several ways:

- Your name will not be used in the study or in any reports or articles written about the study. Instead, a number code or pseudonym will be given to each person.
- Information collected during observation of POP, clinic and CHCNUP activities will be held in the strictest confidence.
- Nurses, doctors, and other staff at VNHS will not be able to see, read, or hear any of the information you provide in a way that will identify you.
- Your employers or supervisor will not have access to any of the information you provide. The only people who will see the research information will be the researcher and her supervisor who is also required to keep all information in strict confidence.
- All information will be securely stored in a locked cabinet in the researchers’ office or stored in a password protected computer file.

- If you worry that information collected during research may identify you, you can ask to have it withdrawn.

VNHS reserves the right to determine whether or how their participation in the project is acknowledged in research reports, articles or presentations.

**Limits of this consent:** The study involves participants at two locations. This consent form pertains to your involvement at the first site. Once details for the second location are confirmed you may be invited to sign consent for participation in any discussions or activities that include people at the second site.

**Data ownership:** Lesley Cerny has sole ownership of all data collected for this study but the cooperative nature of this research is recognized in several ways. Participants will have an opportunity to review and discuss early results before these are discussed with VNHS staff and presented in the PhD dissertation. Copies of reports, articles and presentations will be reviewed with VNHS contacts, Dr. David Tu and Doreen Littlejohn, before being submitted for publication or presentation. VNHS retains the right to decide whether or how VNHS's participation in this study is acknowledged. If there are disagreements in analysis between the researcher and participants/VNHS, appropriate conflict resolution strategies will be employed, such as including objections in articles. Results of this study will be presented in reports, articles, and at health care meetings and conferences. The researcher may use this research in future analysis, but all research information will be destroyed after 10 years. A copy of research results will be made available to staff and members/patients at VNHS. Additional copies can be obtained by contacting Lesley Cerny, PhD Candidate c/o Department of Sociology and Anthropology, Simon Fraser University.

This study has been approved by Lou Demerais, Executive Director, VNHS. No other Aboriginal organizations or Band Councils were consulted for approval. Your honest feedback is welcomed and encouraged. Any concerns or complaints about the study can be directed to Dr. David Tu or Doreen Littlejohn at VNHS, or to Dr. Hal Weinberg, Director, Office of Research.

**Consent:** You do not give up any of your legal rights by signing this consent form. A copy of this consent form will be given to you for your own records. If you prefer, Lesley Cerny may keep your copy of the consent form in a locked file until you request it. Any consent forms left in Lesley's care will be destroyed 5 years following completion of this study. For questions about this study please contact Lesley Cerny. By signing this consent form you agree to participation in the study described above.

I have requested that Lesley Cerny keep my copy of this consent form in a secure, locked cabinet until I request it. Yes  No

Signature of Participant

Date

\_\_\_\_\_

\_\_\_\_\_

Please Print Your Name

Contact Phone Number

\_\_\_\_\_

The Best Way to Contact You

## Consent for participants interviewed following observations of their doctor's visit

**PhD Project Title:** "Two worlds, one hope?" A multi-sited ethnography of how biomedical discourses of antiretroviral drugs interact in two contexts to influence patients' access to and use of drugs.

**Principal investigator and contact information:** Lesley Cerny, PhD Candidate, Department of Sociology and Anthropology, Simon Fraser University. *The study is supervised by Dr. Dara Culhane, Department of Sociology and Anthropology, SFU. The study is funded by a Canadian Institute of Health Research HIV/AIDS Research Fellowship.*

**The purpose of the study** is to provide new insight into the factors that influence peoples' use of ART. The study aims to do this by comparing providers and patients' understandings of and responses to ARTs in Canada and in a poor country. The study examines:

- how health providers and patients understand ARTs
- how these understandings influence providers' and patients' responses to HIV/ART
- how histories of colonialism and social conditions affect ART provision and use.
- how the practices of providers help or hinder peoples' access to or use of ART.

The study is expected to provide information that will help VNHS strengthen existing services for people living with HIV and those using ARTs.

**Participation is voluntary** and you can withdraw at any time without any negative effect to the health care you receive at VNHS. You can refuse to answer questions, and refuse to be interviewed. You can stop participating at any time. No questions will be asked. If you worry that information collected during research may identify you, you can ask to have it withdrawn.

**Information for the study is being collected** from: 1) observations, 2) interviews, 3) documentary sources, 4) ad-hoc consultations and 5) focus groups.

**Observations:** Observing the visit between you and your doctor helps me to better understand what its like to live with HIV and receive HIV and ART services. I am also observing everyday interactions between staff and members/patients in POP, the clinic, and the CHCNUP study.

**Interviews :** I am inviting you to participate in an interview to learn how you experienced the doctor's visit. If you agree to participate I will ask questions such as what you liked, did not like, and how you understood the information discussed. If you agree, I will record the interviews. If you prefer, I will take notes for recall purposes. If you have any questions about your health care, I will ask you to talk to your doctor or a nurse in POP. You can ask to see and discuss interview transcripts up to 2 months after the interview.

**Documents:** To get a better understanding of your experience, information from our interview will be linked with my observation of your medical visit and selected information on your health records at VNHS, and selected survey responses you completed for the CHCNUP study.

Looking at your medical records will show me how your doctor understands your health and whether this is the same or different from your views. My review of your health records will look at laboratory records of your health, providers' notes of the visit, your ART medications and notes related to this, and letters from specialists. I will make brief notes from your records for recall purposes, but no information that can identify you will be recorded. Your health records will never leave VNHS and will only be reviewed in a private area of the clinic or POP.

If you also participated in the CHCNUP study, I will also review your survey responses to questions that relate to ART. I am not looking at whether survey answers are “right” from a doctors’ perspective, or in changing what you are doing (or not doing) with ARTs. Rather, I am interested in how *you* understand medical information, how *you* understand visits with health providers (ie: what helps, what doesn’t and why), and what *you* see as important to your life and health.

**Ad-hoc consultations:** I may ask you to participate in a later interview to help me better understand specific aspects of your life in the DTES. If I approach you, you can refuse to participate. If I approach you and you agree to participate, you will not need to sign another consent form.

**Focus groups:** All participants will be invited to participate in a group discussion of early results of the study. This will occur before results are reported in the PhD dissertation, or included in any other articles or presentations of this research. If you sign this consent, you agree that I may contact you later and invite you to participate in a focus group.

Quotes gathered from interviews and focus groups may be used in research reports or other publications, but anything that might identify you will be removed or changed.

**Signing this consent** means you agree to:

- Participate in an interview following observation of your medical visit
- Let me look at health records of your medical visit at Vancouver Native Health clinic, take notes and include these notes in my research.
- Let me look at your survey responses for the CHCNUP study and include them in my research.
- Let me invite you to participate in a later interview (as needed)
- Let me invite you to participate in a group discussion of preliminary findings at the end of the study.

**Risks and Benefits:** There are no known physical risks for participating in this study. You may be concerned that information you share with me in interviews will be reported to your provider. Your identity will not be released without your consent unless required by law or other regulations. Your participation in the study will provide information to help improve health services for people living with HIV in the Downtown Eastside.

**Confidentiality:** The information you provide will be held in the strictest confidence. Your confidentiality will be protected in several ways:

- Your name will not be used in the study or in any reports or articles written about the study. Instead, a number code or pseudonym will be given to each person.
- Nurses, doctors, and other staff at VNHS will not be able to see, read, or hear any of the information you provide in a way that will identify you.
- The only people who will see the research information will be the researcher and her supervisor who is also required to keep all information in strict confidence.
- All information will be securely stored in a locked cabinet in the researchers’ office or stored in a password protected computer file.
- If you worry that information collected during research may identify you, you can ask to have it withdrawn.

VNHS reserves the right to decide whether or how its participation in this study is acknowledged.

**Limits of this consent:** The study involves participants at two locations. This consent form pertains to your involvement at the first site. Once details for the second location are confirmed you may be invited to sign another consent for participation in any discussions or activities that include people at the second site.

