Nursing and Nation Rebuilding: An Ethnography of Care in the Context of Indigenous Self-Determination

By

Megan K. Muller

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Carleton University
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Abstract

Culturally safe care is gaining traction in health policy, yet the health disparities faced by Indigenous populations persist. In addressing this discrepancy, this thesis addresses the different ways culturally safe care is defined, envisioned, and applied within health policy, Indigenous nursing practice, and within Nuu-chah-nulth communities. The research was conducted in partnership with the Nuu-chah-nulth Tribal Council (NTC) Nursing Services on the Canadian West Coast. This project involved two years of collaborative ethnographic field research based in Port Alberni, BC. My role at the NTC was both a student ethnographer and an embedded health systems researcher. Data was also collected from semi-structured narrative interviews with nurses, community members, and health leaders and participant observation of nursing visits, health-related workshops, and community events. Findings illustrate that Indigenous self-determination enables relational modes of care, which have increased access to health services by providing a site for individuals to overcome past trauma, as well as a platform for nation-rebuilding and collective healing. At the same time, a biopolitics imbued with colonial logics continues to justify the lack of health services available in Indigenous communities. Indigenous patients are subjected to racialized stereotypes which affect the quality of care they receive. These practices are perpetuated through the discourse that the health care system is experienced the same by all Canadians. I challenge this by demonstrating how Indigenous peoples are subjected to constructs of “deserving” and “undeserving” patients informed by a truth discourse which is enacted through clinical decision-making and specific biomedical care practices which normalize structural racism. By understanding care practices as the subject of multiple ontologies, the collective modes of care performed informally within Nuu-chah-nulth families or during social gatherings expand the kinds of care afforded in biomedical settings, by emphasizing an ontologically relational nature of being. Ultimately, Indigenous modes of care are both marginalized by and actively transforming biomedical standards of care in western Canada. This produces simultaneous, oppositional movements between enacting relational modes of care and the colonial legacy linked to systemic racism that oppresses Indigenous ways of knowing and excludes Indigenous peoples from the ostensibly universal public good of health care.

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Preface

On Nuu-chah-nulth *hahoolthi* (traditional territory), I am *mamat'n'i*: an outsider, a person with no home. However, over the two years I was living in Port Alberni, I did come to regard the town and the Nuu-chah-nulth Tribal Council Health Department as my home. Certainly, it was where my *ticcma* (heart) was during this time. I was initially connected to the NTC through long-standing friendships that I had developed through my years spent living, working, and studying on Vancouver Island. The outcome of this work is largely due to the supportive and inspired mentorship I received from the NTC Nursing team. A key objective of my research, as outlined in a collaborative research agreement with the NTC, is to support the NTC Health Department with evidence of the impact of their approach to health care delivery as well as provide recommendations for educating new professionals or for advocacy purposes. As a result, when I first arrived, I was immediately put to work, not only as a student ethnographer, but also as an embedded health systems researcher. However, the fact remains that I am *mamat'n'i* and there are pertinent reasons to question the role of a non-Indigenous researcher writing about access to health care in Indigenous communities. I have tried to address this in various ways: through how I connected with project contributors, how I approached the work, and how I described what I have learned. I have attempted to carry this work through *isaak* (respect), gratitude, and compassion. But there are likely a thousand things I have yet to learn. And being an imperfect human, shaped by my own background, education, and worldview, there are likely a thousand things more which I will never grasp. As such, I

invite anyone who reads this text to challenge me, to correct me, and to help to carry the dialogue forward.

Chapter 1: Introduction

This thesis presents an ethnography of care in the socially and politically contested space of Indigenous self-determination, especially as it relates to efforts to improve access to basic health services on Vancouver Island, British Columbia. In collaboration with the Nuuchahnulth Tribal Council, this thesis explores the ongoing impact of colonial policy frameworks that pose barriers to expanding health services and enhancing culturally safe health care to First Nations¹ communities, and how self-determination over health care administration is cultivated in contradictory political climates. What was impressed upon me during my two years of field study with the Nuuchahnulth Tribal Council (NTC) Nursing Services, was that health care experiences are both profoundly influenced by historical and systemic conditions, while also intimately personal. In the context of NTC nursing, each health care encounter is relational and rooted in Nuuchahnulth values and culture, while also circumscribed by biomedical nursing standards. A health care experience (or the failure to access needed care) has the potential to result in enduring a limited socio-material reality, or a collaborative enactment of a shared vision for better care. A health care experience can be oppressive, transformative, a bit of both, or simply mundane. Ultimately, health care experiences in the context of systemic inequity can be healing while they can also be traumatizing.

¹ I use the term First Nations to reflect that this research was conducted with Nuuchahnulth First Nations. However, I also recognize the likelihood of similar or overlapping experiences shared by Metis, Inuit, and other Indigenous Peoples living in British Columbia and Canada more broadly and so I also use the term Indigenous. Use of the term Aboriginal is applied to reference the language used in Canadian legislation.

This dissertation is an exploration of the multifaceted ways the relationship between Indigenous communities and colonial health care systems are negotiated through cultural resurgence, self-governance, and everyday acts of collective and relational care. In this work I address divergent logics of care found in biomedical structures of acute and primary care, Indigenous governed health care delivery, and the more everyday modes of care that operate within families. However, it is important to note that none of these modes of care can be understood in their present form in isolation from the others.

The NTC provides nursing services for members of affiliated Nuuchahnulth communities and has established a unique framework for care provision which combines Indigenous traditions, values, and beliefs with the framework of cultural safety as well as conventional nursing regulations². With the transformations occurring in Indigenous health governance in British Columbia, new language and concepts have emerged to envision new ways of providing care that are more rooted in Indigenous worldviews and speak specifically to Indigenous experiences. One such term, “culturally safe care,” is an integral concept to understanding the discourse around Indigenous health in Canada. I have adopted the term “cultural safety” as a key way of framing and talking about my own research, as the concept offers a way of bringing attention to the quality of care issues and healthcare experiences in Nuuchahnulth territories. In later chapters I nuance the different ways this term is taken up in policy, different segments of the health care system, and within Indigenous communities on the west coast of Canada. However, in a general sense, cultural safety can be understood as a dedicated and reflexive attention to

² As established by the Nurse Practitioners Regulation under the Health Professions Act of BC (2008).

the way power imbalances (both among dominant and marginalized groups as well as between health care professionals and patients) work through health care encounters to reproduce relations of oppression.

By examining the ways in which cultural safety is implemented or aspired to, I illustrate the multifaceted networks of care—which span from family life, to community nursing advocacy, to hospitals and clinics—that seek to mitigate or challenge inequity in access to health care. These networks of care involve the complex layering of jurisdictions including federal, provincial, tribal council and band council, that support, fund or operate health services. The negotiation between different modes of care promoted by these various forms of health governance can also work to perpetuate the uneven distribution of health inequities between settler and Indigenous communities.

In illustrating this, I draw on an understanding of care as the concrete acts and relationships that reveal the diverse ways health services are implemented and accessed. Rather than viewing care as a sentimental disposition – or inherently good – I view it as a framework for practice grounded in cultural assumptions about the nature of health and human relationships. I use the term “care” in the anthropological sense as a mode of social and affective organization through which people construct affiliations and obligations. In other places, I use the term “health care” to reference the institutional sites of care which people access, such as clinics, hospitals, or nursing stations. By “health care experiences” I am referring primarily to clinical encounters that occur in situations such as urgent care clinics, emergency departments in hospitals, or during appointments with general practitioners, or during home visits with the NTC nurses.

While I am interested in critically interrogating modes of care that operate within the health care services available to Nuuchahnulth communities, I am also interested in the other ways care manifests, such as through Indigenous nursing, among families, and during community events. In this sense, there are many ways to organize, practice and conceptualize care, and multiple ways patients may interpret and respond to that care. In extension, practices of care are applied in navigating the disjuncture between the ideal of welcoming cultural difference in the clinic and, in practice, the alternative forms of healing and caring that challenge biomedical norms.

Corresponding with this approach, this thesis explores the meanings and expectations attached to culturally safe care from different perspectives by posing the question of how culturally safe care is defined, envisioned, experienced, and practiced within health policy, NTC nursing services, and Nuuchahnulth communities, and in what ways these approaches contrast or coincide. Through this research, I have gained insight from NTC nurses in their efforts to enhance health services, both in terms of quality (safety) and access (equity). A key objective of my research, as outlined in a collaborative research agreement with the NTC, is to support the NTC Health Department with evidence of the impact of their approach to health delivery as well as provide recommendations for educating new professionals or advocacy purposes. For instance, what are the most prevalent community care needs and expectations? How does culturally safe or unsafe care delivery influence health outcomes and health behaviors? How do NTC nurses translate culturally safe care into practice? What are the opportunities to connect with and empower individuals to make positive steps towards increasing their health and wellness? How is the NTC nursing practice circumscribed by

overarching policy or lack of resources? What are the sites where current policy fails to support access to culturally safe care?

In addressing these questions, I worked collaboratively with and learned from the NTC *Hupiimin Wiikšahiiy'ap* (helping us to be well) Nursing Services. I also learned from NTC nursing staff, clients, Nuuchahnulth Elders, and community health leaders, by shadowing NTC nurses, conducting semi-structured interviews, attending community healing events and workshops, travelling to visit remote communities, hanging around at community health clinics, and attending Elder's lunches, health fairs, cultural nights, or community meals. Through my alliance with the NTC and Nuuchahnulth communities, a goal of this work has been to challenge health inequity and structural racism. As part of this commitment, in my work I center Indigenous theory by investigating health care encounters as situated within settler-Indigenous relations and by addressing the affective and material dimensions of care – both the sites of social suffering and spaces of hope.

Overwhelmingly, my research demonstrates that self-determination in health care administration reduces health inequities by increasing both access to and appropriateness of services. The self-determination of health services enables Indigenous resurgence, where Indigenous approaches to healing and wellness are actively transforming health care in western Canada. However, at the same time, colonial processes continue to perpetuate anti-Indigenous racism in health care, exclude Indigenous communities and oppress alternative visions for care.

The purpose of this introductory chapter is to situate my work both contextually and theoretically. I first introduce readers to the NTC Nursing Services and Nuuchahnulth communities. This is followed by an overview of the theoretical influences that

address the underlying concerns that preoccupy this work, such as how to address social suffering without objectifying its supposed “victims,” or how to describe Indigenous and biomedical modes of care as co-constituted, or even working together, rather than as incommensurable. In doing so I bring into conversation Indigenous relational and critical theoretical paradigms, and outline the influences I have drawn from, including critical medical anthropology, Indigenous relational paradigms, especially the Nuuchahnulth theory of *hishook-ish tsa’walk* (everything is one), recent ethnographic theorizations of care, and affect theory.

Research Setting

The Nuuchahnulth nations include numerous communities spanning across the west coast of Vancouver Island and the Olympic Peninsula of Washington State. There are fourteen First Nations represented by the Nuuchahnulth Tribal Council, including (roughly from north to south) Kyuquot/Chickliset, Nuchatlaht, Ehattesaht, Mowachaht/Muchalaht, Hesquiaht, Ahousaht, Tla-o-qui-aht, Yuułu?il?ath, Toquaht, Uchucklesaht, Tseshaht, and Hupacasath, Huu-ay-aht, and Ditidaht. The Nuuchahnulth *ha’hoolthi* (traditional territories) are composed of temperate rainforest, Pacific coast and tributaries, and mountainous ecosystems. Key resources include cedar and salmon; however, communities traditionally harvest diverse species of fish, marine mammals, mollusks, berries, plants, and wild game. Nuuchahnulth communities practiced complex methods of preparing and preserving foods. Before European contact, communities moved seasonally to follow harvesting cycles (Maquinna George, 2003). Salmon streams afforded important resources, managed by the *ha’wiih* (hereditary chiefs), and sometimes presented a source of conflict between nations (Maquinna George, 2003). With

colonization and the settling of Nuu-chah-nulth territories, families increasingly moved to modern single-family homes.

With colonization came the parceling out of reserve lands and colonial control over regional fisheries. Often, Indigenous nations on the Canadian west coast were allotted significantly smaller tracts of land, under the assumption that seafaring people did not require extensive land. The establishment of residential schools, such as the Alberni Indian Residential School which was in operation between 1892-1973, segregated children from their home communities to undermine cultural values and instill a European sense of discipline. Communities responded to urban encroachment, poor sanitary and living conditions on reserve, and the forced removal of their children, through political mobilization; “economic strength and political skill enabled Aboriginal leadership to win concessions from Indian Agents, [and] to do battle with land-grabbing municipalities” (Kelm, 1998, p. 55). Indeed, there is a significant legacy of political action led by both the Nuu-chah-nulth Tribal Council and the respective First Nations.

Today, many of the First Nations within the central region, including Tla-o-qui-aht, Yuułuʔiłʔatḥ, Toquaht, Tseshat, and Hupacasath are located on or in proximity to highways and populated municipalities. However, many other Nuu-chah-nulth nations are geographically remote and can only be accessed by unpaved logging roads. Some communities, including Kyuquot, Ahousaht, Hesquiaht and Opitsat (a Tla-o-qui-aht village) can only be accessed by boat or air travel. The increased travel involved in accessing these communities greatly impacts how health services are provided.

The Nuu-chah-nulth Tribal Council began as a political alliance in 1958, titled the West Coast Allied Tribes. It was incorporated into a non-profit, the West Coast District

Society of Indian Chiefs, in 1973 and was later named the Nuuchah-nulth Tribal Council (NTC) in 1979. Since this time, the NTC has increasingly gained control over services such as fisheries, child welfare, education, economic development, and health services. The NTC aims to advance the role of the *ha'wiih* (hereditary chiefs), protect *ha'hoolthi* (traditional territories), and pursue self-determination through facilitating community control over social and economic services (Nuuchah-nulth Tribal Council, 2017a). This also includes a mandate to advance Nuuchah-nulth language, beliefs, and way of life. The NTC is comprised of an elected executive committee and functions as both a service provider and a site of political advocacy. Amalgamations between nations and the creation of the NTC was a point of cultural renewal and to “wrestle power from Ottawa” (Seitcher, n.d., p. 8); creating opportunity to return to *hahuupa* (teachings) in informing decision-making regarding the welfare of Nuuchah-nulth communities.

The *Hupiimin Wiikšahiiy'ap* (helping us to be well) Nursing Services are provided in collaboration with each of the First Nations, primarily on-reserve (excepting some services provided in urban communities and West Coast General Hospital, WCGH). Providing services in-community requires nurses to engage in an extensive amount of travel by plane, boat, or by renting heavy-duty trucks to drive on the logging roads. The nurses work as a team to ensure services are available in-community as regularly and as often as feasibly possible, which can be challenging with a limited number of staff and vast geographical area to cover.

Nursing services provided by the NTC included, at the time of writing, community health nursing, home care, a First Nations Advocate Nurse at WCGH, a nurse navigator, and health promotion. Community health nurses offer maternal and child

health care, immunizations, prenatal and postpartum visits, screening and prevention of communicable diseases, and health education events in communities. Home care nursing includes monitoring and assessing chronic conditions, developing care plans, medication management, foot care for diabetics, and developing chronic disease management programs with communities. The First Nations Advocate Nurse supports patients and their families while in hospital, and the nurse navigator supports clients throughout their healthcare journeys, including transitions from hospital to homecare, and connecting clients to available supports and resources.

Nurses working in remote communities play an important role politically and socially because of their regular presence within the Nuu-chah-nulth communities, and their position as liaisons and leaders navigating between broader health systems and the communities. The NTC Nursing Services is funded primarily by the First Nations Health Authority, however they also receive contracts from the regional health authority, Island Health (IH). While funding is generally transferred from the First Nations Health Authority to the NTC, some Nuu-chah-nulth First Nations have signed treaty agreements in which case the nation directly contracts the NTC for services. There are also First Responders (volunteers trained in first aid treatment), Community Care Aides, and Community Health Representatives, positions which are typically occupied by community members (Sangster-Gormley, 2011).

The NTC area of coverage provided to the fourteen nations is divided into three regions (see Figure 1). In addition to care provided in communities, the NTC provides services for urban members, including wellness events, health outreach services, and a drop-in clinic. NTC nurses often serve as the first point of contact for community

members and many of the Elders living off-reserve prefer to see NTC nurses. The NTC has cultivated a unique nursing culture by guiding their practice through the NTC mission statement, cultural safety, and framing the “independence of Nuu-chah-nulth-aht³ as a strong priority” (Nuu-chah-nulth Tribal Council, 2017b). Nurses employed by the NTC are required to train in courses on ‘Indigenous cultural competency’ and ‘nursing the Nuu-chah-nulth way’. Some of the NTC nurses are Nuu-chah-nulth, and many are Indigenous to other nations. Others still identify with having settler ancestry. Some families include multiple generations of nurses who have served Nuu-chah-nulth communities, and some nurses have married into the communities. However, it seems all NTC nurses who have been employed for several years have longstanding and heartfelt connections with the communities they work in.

The NTC Nursing Services do not provide acute or primary care; this is made available by the province in remote communities by locum doctors⁴ or outpost nurses. The Province of British Columbia employs visiting physicians, whom Nuu-chah-nulth community members can access anywhere between a few days per month, to several days per week, depending on the community. The context in which health professionals work is particularly challenging not only because of the geographic distances, but also the

³ Nuu-chah-nulth-aht refers to members (*aht*) of Nuu-chah-nulth communities.

⁴ A locum doctor is a physician who works temporarily in place of a permanently established physician. Locum doctors typically live out of community and travel in to provide health services.

nature of illnesses (particularly a high burden of chronic illness) suffered by Indigenous Peoples, and limited resources available for health provision.

Figure 1: Map of Nuu-chah-nulth Territories

Health disparities faced by Indigenous Peoples in Canada have been demonstrated in numerous studies, through indicators such as health status, life expectancy, morbidity rates, and access to health services (Adelson, 2005; Gee & Ford, 2011; Kurtz et al., 2008; Million, 2013). For instance, life expectancy for Indigenous Peoples in Canada “can be contrasted as well to that of non-Indigenous, the latter enjoying 5 to 8 years longer life expectancy than Indigenous peoples” (Czyzewski, 2011). Disparities faced by Indigenous

Peoples living on Vancouver Island include a higher prevalence of diabetes and some cancers, and lower rates of access to care (First Nations Health Authority, 2019). In a recent review of services, the NTC Health Department identified 90 Elders living in the city of Port Alberni with chronic health conditions and unmet health needs because of a lack of access to culturally safe health services. Access to adequate health care is an immediate and ongoing concern held by the NTC and community members. What needs to be understood, theorized, and practically addressed is why, despite the incredible efforts invested by the NTC and Nuuchahnulth First Nations in mitigating health inequities, there continues to be unfaltering persistence of anti-Indigenous discrimination in health services as well as bureaucratic barriers to making health services more available and accessible.

Theoretical Influences

In my writing I attempt to develop a fluency between framing the discussion via my grasp of Indigenous theory and western philosophy and social theory. I also track between sets of languages: that of an anthropologist, of the discipline of nursing, of health policy analysis, and also the more colloquial language I encountered in the field. My intention is not to overcomplicate but to retain a sense of the position from which I am located, as a Euro-Canadian woman with western education and a rural, working-class family background. Anthropologists have often claimed their relevance as translators or mediators between multiple arenas of action and discourse, so I take this legacy as also informing my approach. I am fascinated with the sites where ontologies may overlap, collide, or at least offer the grounds for some comparison, and allow us to

better understand both *through* one another⁵. My approach is an eclectic one, but in so doing, I aim to retain the distinctiveness and lineage of the different sources I draw from.

In proposing this project, I wrote of my hopes to challenge common-place tropes such as the epistemological divide between Indigenous healing and biomedicine, as well as the common tendency to depict Indigenous peoples as passive victims of colonization. I have attempted to do this by situating the object of investigation as networks of care that link individuals, communities, and institutions under the shared goal of improving health in Nuu-chah-nulth communities, rather than framing the object of study as a specific location or group of individuals. Examining the Indigenous modes of care implemented by the NTC which have expanded or challenged biomedical norms requires a sensitivity towards the relationship between health care experiences, colonial health systems, and Indigenous governance. Through this focus on relationships (between care providers and patients, as well as between divergent modes of care), I have found that an integration of relational and critical paradigms to be the most fruitful approach. As such, I largely draw my interpretations from Indigenous theory outlining relational ontology, including the Nuu-chah-nulth concept of *hishook-ish tsa'walk* (everything is one), as well as critical medical anthropology, primarily drawing from post-structuralist adaptations of the concept of biopower.

⁵ For example, Cree scholar Margaret Kovach describes how a tribal epistemology is compatible with relational qualitative traditions, including participatory action research, phenomenology, narrative, social constructivism, feminist inquiry, autoethnography, anti-oppressive approaches, and critical reflexivity. What these approaches share with Indigenous research methods and tribal epistemology is the focus on the process of interpretation between researchers and the subject of study, wherein reflexivity can be used as an indicator of validity (Kovach, 2009).

Anthropology and Suffering

In 1904, George Hunt assisted Franz Boas with the “removal” of a sacred Whaler’s Shrine in Yuquot that belonged to the Mowachaht/Muchalaht Nation and sold it to the American Museum of Natural History in New York City, with devastating consequences for the community. This was one of the first interactions with a long lineage of anthropologists, ethnologists, and archaeologists who have worked with Nuu-chah-nulth communities⁶, leaving varied legacies behind them. Many of these encounters were experienced by the communities as a form of colonialism. Sacred relics and regalia were removed, intrusive questions about ceremonies were posed at a time when they were illegal to perform⁷, and cultural practices were represented in anthropological texts and museum exhibits as exoticized fantasies for European consumption. In my own work, I am inevitably building on what my academic predecessors have produced and re-experiencing the settings and traditions that inspired their creations. I keep these influences in mind in hopes of learning from both the contributions and harms they committed in terms of Nuu-chah-nulth sovereignty and cultural integrity.

Michel-Rolph Trouillot, a Haitian anthropologist, has stated that the symbolic order upon which anthropology sits must be reconfigured in order to disengage from this pattern of depicting the “savage other” (Trouillot, 2003). In response, Joel Robbins has suggested that a shift towards studying the ‘suffering other’ has been used as an answer

⁶ Notable others include Edward Sapir (1911), Edward Curtis (1916), Philip Drucker (1964), Hugh Brody (1994), Michael Harkin (1998), and Alan McMillan (1999).

⁷ This was due to the potlatch ban (1884-1951), a piece of Canadian legislation that made all forms of ceremony illegal.

to the questions brought up by the crisis of representation⁸, which brought explicit attention to the colonial roots of the discipline (Robbins, 2013). According to Robbins, the discipline came to abandon the customary “savage other” as an object of analysis in favour of investigations of suffering, trauma, and violence as a site to explore “empathetic connection and moral witnessing based on human unity” (Robbins, 2013, p. 453). Sherry Ortner refers to this turn as “dark anthropology”; an “anthropology that emphasizes the harsh and brutal dimensions of human experience, and the structural and historical conditions that produce them” (Ortner, 2016, p. 49).

This trend in anthropological work shifted the focus almost exclusively to questions of power and inequality, shedding light on the complicity of the discipline with processes of colonialism. However, the focus on suffering has allowed anthropologists to skirt the issue of how they represent culturally different ‘others’ by focusing on the assumed universality of human pain and trauma. A tendency amongst texts which we can consider as ‘dark anthropology’ is that they magnify aspects of suffering and violence as a unifying element amongst all cultures, and through their humanitarian undertones, promote a western definition of ethics and morality (Robbins, 2013). This issue is noteworthy, given the tendency within Indigenous health research to over-emphasize health deficits, inadvertently providing justification for paternalistic health interventions (Czyzewski, 2011; Million, 2013). Additionally, ‘dark anthropology’ produces a voyeuristic fetishization of suffering as “interesting” subject matter, thereby perpetuating

⁸ The “crisis of representation” refers to a historical moment where anthropologists abandoned the sense of the authority and objectivity attached to the perceived ability to represent a ‘native’ point of view (Trouillot, 2003).

the trend to objectify and exoticize the experiences of Indigenous Peoples for academic consumption (Ortner, 2016; Robbins, 2013).

Interestingly, the focus on cultural difference which the anthropology of suffering seeks to reduce is what Robbins views as the strength of more traditional anthropological approaches. Robbins argues that anthropologists have “lost hold of the cultural point and the critical potential of the notion of difference that it once allowed us to realize in our work” (Robbins, 2013:447). Robbins’ solution is to attend to elements from both modes of representation – cultural difference from the ‘savage other’ and social struggle from the ‘suffering other’ – by reframing the object of analysis. He suggests anthropologists examine “the different ways people organize their collective lives in order to foster what they think of as good, and to study what it is like to live at least some of the time in light of such a project” (Robbins, 2013:457). Robbins suggests that through such an approach objects of anthropological analysis could include social processes such as morality, ethics, care, gift-giving, and wellbeing, among others. This approach implies that rather than illustrating a *people*, or a practice of a particular people, some recent authors have moved towards illustrating social constructions as *processes*, that act on individuals or work to shape lived realities.

Though initially enamoured by this approach, it did not allow me to theorize my way out of the suffering I was forced to confront while in the field. In Indigenous health, power imbalances exist not only between the patient and care provider, but also between colonial institutions which perpetuate inequalities in access to health care. As situated within a settler society, Aboriginal health policy in Canada cannot be extricated from broader political debates particular to the late colonial relationship between Indigenous

people and Canadian state institutions. I have found that one cannot retain the “critical potential” of ethnography without explicitly identifying instances of injustice; where there is injustice there is inevitably suffering.

Yet, how to develop a frank discussion about the existence of health inequities without playing into the old colonial tropes of Indigenous peoples as victims? How to write about suffering in a way that does not victimize protagonists, or objectify or fetishize their experiences? This is an unresolved question I continually contend with throughout this work. One way I have researched and wrote in response to this question is by reframing the object of analysis from the analytically alienated ‘other’ to interactions *between* the anthropologist *and* others, as well as *amongst* agents themselves inhabiting various positions of power. My analysis centres on processes of negotiation and interactions surrounding the changing of health care delivery as opposed to Indigenous ‘other’ medical practices as a discrete and separate entity. I am interested in the process of multiple modes of care converging in the creation of a new definition and practice of wellness, and how it is defined by and negotiated between a number of stakeholders engaging in the same (though perhaps differently conjectured) goal to improve health care in Indigenous communities in western Canada.

Because I was confronted with suffering in the field, I felt I had to reacquaint myself with “dark anthropology” and to reconcile these approaches. Although I was initially aligned with the critiques raised by Robbins, I am now in agreement with Ortner that it is limiting to construct these two approaches (dark anthropology and anthropology of the good) as oppositions. I have found it impossible to write without reconciling them; to look critically at the societal causes of inequality *and* to examine the construction of local

moral worlds (Das, 2015), including ethics and care as a response to these conditions.

Working in the context of settler colonialism, I believe the root of the distinction between an anthropology of suffering and an anthropology of “the good” is the degree to which change in material conditions is believed to be possible. Instead, I was compelled to find a means of analysis that also incorporated what I had been taught about compassion, hope, persistence, resurgence, and what it means to be a part of a community. What was needed was a way to write about these dynamics as well, and ultimately how health care is being transformed in incremental ways through the advocacy of Nuuchahnulth communities.

In reflecting this, I have been influenced by the work of medical anthropologist Veena Das, who consistently integrates both of these approaches. Although she was a leading scholar in the development of the anthropology of social suffering, she has remained adamant that both insight into suffering as well as how ‘the good’ is constructed is necessary. For instance, in her ethnography *Affliction* (2015) on access to care in poor urban neighbourhoods in Delhi, she examines the lives of families and local practitioners as they negotiate limited resources and options for health care. Her approach is to “look at affliction in terms of not only a theology of suffering but also a political economy of everyday life” (Das, 2015, p. 25). Das articulates the pathways between large scale changes and the forms of care enacted in everyday life. Her approach is to, “show how singularity of lives might be seen as the coming together of multiple forces-political, economic, affective, aesthetic-and [...] to reflect on what these lives might tell us about the grand projects of health reform” (Das, 2015, p. 22).

Similarly, I have adopted a multi-level analysis by investigating networks of care linking broader health policy, enduring Indigenous governance structures, local health services and leadership, as well as the individual health care providers, patients, and their families. Networks of care link together diverse actors through professional relationships, policy frameworks, and singular acts of care involved in the provision of health services. Thus, I write about relational modes of care that not only attend to the ill but mitigate historical trauma, as well as exclusionary care that systemically abandons or dismisses the pressing health needs of Indigenous patients seeking care. My effort to write about health care as containing potential to be both oppressive and transformative is reflected in my theoretical approach. I centre Indigenous relational theory while also drawing from critical medical anthropology, social suffering, biopower, and affect theory to explore the lingering affects and social implications of different modes of care.

Critical Approaches

As both a theoretical and practice-based approach, critical medical anthropology (CMA) responds to challenges in health or the alleviation of illness. An emphasis is placed on the interaction between macro level political economy, national political and class structures, health care institutions, community-based practices and beliefs, and the micro level of disease, experience, behavior and meaning (Singer, 1995). CMA contains an inherently “emancipatory mission”; beyond gathering knowledge about health inequities, CMA aims to “change culturally inappropriate, oppressive, and exploitive patterns in the health arena and beyond” (Singer, 1995, p. 81).

Lock and Scheper-Hughes have adapted this formulation to what they term “critical-interpretative” medical anthropology, which brings investigations of

signification and meaning into conversation with power and knowledge of the body (Lock & Scheper-Hughes, 1996). I understand Lock and Scheper-Hughes' formulation as compatible with Ortner's call to bring together studies of meaning and ethics into conversation with analysis of structural power. This orientation brings attention to embodied, "mindful" lived experience. Similarly, Biehl et al. call for a conceptualization of the cultural dynamics of health and illness "in which the collective and the individual are intertwined and run together and in which power and meaning are not placed in theoretical opposition but are shown to be intimately linked in an intersubjective matrix" (Biehl et al., 2007, p. 14).

A common way anthropologists have applied a critical-interpretative approach is to illustrate illness experiences as an expression of dissent or act of refusal (Hunt, 2000; Lock & Scheper-Hughes, 1996). However, I find it problematic to frame illness experiences as "the safest way to portray opposition" (Lock & Scheper-Hughes, 1996, p. 64) because while it politicizes lived experience, it works to move away from the materiality of illness experiences, constructing them almost as a (albeit often subconscious) *choice*. Furthermore, spaces of medical intervention are not experienced as safe for many Indigenous Peoples. Thus, rather than looking at illness experiences as a mode of resistance, I am more interested in the responses to illness, or the modes of care, as resistance.

What I retain from CMA and critical-interpretative medical anthropology is the dual focus on meaning and power, on instances of injustice and suffering, as well as the agency expended in caring for one's relatives and working to improve the quality of care available in Indigenous communities. I feel it is necessary to retain the significance of

cultural difference within the context of my research, as medical anthropologists and Indigenous scholars have long insisted on the importance of empowering Indigenous practices and conceptions of wellness as a strategy for reducing disparity in health status (Martin Hill, 2009). Cultural distinctiveness is irrefutable given that these communities have been contending with the impacts of violent cultural assimilation. Understanding the concrete implications of care and how they are bound up with material and political constraints is a necessary step in understanding the complexities of providing health care in remote First Nations communities.

Similar to CMA, the concept of social suffering emerged as a response to the turn towards “dark anthropology” in the 1990s by medical anthropologists, notably Arthur Kleinman, Veena Das and Margaret Lock. The framework was developed to reveal how “social suffering results from what political, economic, and institutional power does to people and, reciprocally, from how these forms of power themselves influence responses to social problems” (Kleinman et al., 1997 ix). Social suffering offers a conceptual means of linking health conditions and individual experiences of illness with socio-political forces and global influences and has subsequently been applied by health researchers working with Indigenous groups in Canada⁹. While an anthropology of social suffering is problematic for all the reasons previously mentioned, it remains useful as a means of

⁹ For instance, medical anthropologist Melanie Rock interrogated how definitions of “sweet blood” structure clinical practice and diabetes interventions in Cree communities in Northern Quebec, utilizing the social suffering perspective to reveal how socio-economic conditions mediate disease prevalence (Rock, 2003). Browne et al., nurse researchers, investigated barriers to primary care faced by Indigenous peoples living in a low-income urban neighborhood and found that use of a local emergency department for primary care was a reflection of social suffering and the intersectional social boundaries that dissuaded Indigenous patients and other marginalized peoples to seek care in other sites (Browne et al., 2011).

interrogating the link between policy, health institutions, and realities of living with illness in the context of health inequity.

In developing a critical analysis, I also draw from poststructuralist theory, specifically the concept of biopower, to illustrate how a biomedical mode of care, through specific policies and practices, is experienced as distinctly exclusionary. Biopower was initially proposed by Michel Foucault to describe a historical shift occurring during the 16th to 18th centuries in how power and control operated within modern nation states. In a regime of biopower, the vitality of individual lives is taken up as an object of political control; “if the old right of sovereignty consisted in killing or letting let live, the new right will consist of making live or letting die” (Foucault, 2002, p. 172). This right of “making live” is enacted through systemized interventions that aim to improve the vitality of populations (Rabinow and Rose 2006). This shift towards biopower as a mechanism of governance was linked to the emergence of capitalism and the management asserted by nation-states over populations and bodies to ensure a productive nation (Scheper-Hughes & Lock, 1987).

The objective of biopower is “governing to produce certain lives rather than repressing ‘life’ generally” (Million, 2013, p. 148). Biopolitical subjects act as consumers managing their own freedom of choice, ultimately in service to a dominant order. For Million, contemporary biopolitics is inseparable from neoliberalism “not only as a set of economic practices, but as a governance and imaginary that infuses ways of life” (Million, 2013, p. 147). Biopower, as a diffuse apparatus of governance in colonial nation states, operates through both the management of populations by way of state interventions as well as through embodied experiences as subjects of the dominant

(settler) social order. In my investigation of biopower, I examine how an ostensibly public good can be structured in such a way that it perpetuates health inequity, as well as the normalization of discriminatory attitudes and practices in health care.

Hishook-ish Tsa'walk (Everything is one)

Shedding light on and offering alternatives to structural inequity requires investigating how power infiltrates our lives in terms of our chances of getting ill, what health care services we may have at our disposal, and how we are attended to by those who provide care to us. However, an attentiveness to the interconnection between an individual act of care and how we organize ourselves socially, economically, and politically provides invaluable knowledge beyond understanding the workings of power and oppression. This attentiveness to links and relationships reveals what it means to care for someone, or how this may be imagined differently in different social contexts. It can also reveal the affective and embodied dimensions of caring, whether a doctor's dismissal in an emergency department, or whether a visit from a community-based nurse that affords a new source of hope. Many of such encounters produce affects that linger, sometimes across generations. These affects coalesce into subjective experiences, that can be expressed as opinions that grow to form discourses or they may lead to actions that ripple out across communities.

I find the Nuu-chah-nulth philosophy of *hishook-ish tsa'walk* informing my thoughts deeply. Nuu-chah-nulth scholar, Richard Atleo, explains that through *hishook-ish tsa'walk*, “all life forms, the two worlds [physical and metaphysical] were experientially one” (Atleo, 2004, p. 10). I was aware of this philosophy before entering the field but was surprised at the extent to which it permeated daily life. I found this

phrase written on t-shirts and coffee mugs; inscribed in project and policy descriptions produced by the NTC; and discussed in casual conversation with knowledge keepers. For example, while visiting Yuquot, I was walking along the trail that leads from the lake to the picnic area and harbour when a Hesquiaht Elder and his small grandson stopped to speak with me for a while. We stood on the shady trail that overlooked a white beach and ocean swells. We covered a great many topics ranging from family conflict, to work and travel. He also spoke to me about *hishook-ish tsa'walk*. He mused that keeping in mind the interconnection among all things allows us to take a unique stance towards conflict, to be able to afford others the space to speak their piece without an urge to respond. He shared how *hishook-ish tsa'walk* informs his spirituality and his daily life. He explained, “every morning I go into the ocean. The salt water is very healing. That is my way of praying but I do not pray with my words. I pray with my body. I feel grateful for the land, and the nature, and that life is very precious. You can see it when you look at the little ones, how precious life is” (personal communication, July 19, 2019). I am not sure if there is one succinct way to explain all the different ways *hishook-ish tsa'walk*, the inherent awareness of interconnection, affects daily conduct, formal protocol, social organization and even belief. However, my understanding is that, as ontologically foundational, it affords a unique perspective on wellness, healing, and care that often contradicts biomedical approaches.

I see *hishook-ish tsa'walk* as not just the interconnection between land, ocean, material, and spiritual beings. It also frames the way I analyze the observations and conversations recorded during my research. For example, I continually return to the interconnection between societal formations and interpersonal experiences, between

political governance and culturally safe care, or individual governance over one's own body, as well as through seeing care as a relational and interconnected act, and through seeing health as a holistic state of being.

My way of enunciating this sentiment – this interpretation of how *hishook-ish tsa'walk* speaks to me in the context of this work – is to speak about relationality. By using the concept of relationality, I would ask readers to consider this concept on multiple levels. Firstly, I ask readers to recognize relational practice as a mode of care, one which is defined in nursing theory and foundational to the Nuu-chah-nulth Tribal Council nursing framework, as well as a useful concept for understanding the responsibilities and expectations informally ascribed to care in Nuu-chah-nulth communities. Alongside understanding relationality as a mode of care, I simultaneously apply the concept as a theoretical position informing my interpretation of the things I was told and observed while conducting this research. Relationality may be a somewhat problematic framework due to the ambiguity created through the ways different intellectual paradigms have taken it up, but I also find in the concept the potential to work as an ontological position for looking at how difference is constructed through encounter (Faier & Rofel, 2014), such as between care providers and patients, divergent healing traditions, and even ideas attached to race and cultural identity, as they are socially constructed in colonial contexts.

Ethnography, and by extension all qualitative research traditions, are often acknowledged as relational in the sense that they are interpretive, interactional, and that information collected is contingent on the development of a relationship between researcher and participants (Kovach, 2009). Relationality has appeared in various forms

as a counter-discourse challenging Western philosophy for some time, as seen in the works of, for example, Friedrich Nietzsche, William James, Martin Heidegger, and Emmanuel Levinas (Reddekop, 2014). To provide a crude generalization, these approaches challenge the Cartesian subject-object dichotomy by emphasizing the role of relationships in constituting subjectivity. The influence of relationality in western philosophy has permeated various academic disciplines, including anthropology and nursing. Julia Eckert has theorized relationality as an anthropological stance by stating that by “theorizing the sociality of difference, we can get hold of the ghosts that we called forth when we [anthropologists] struggled for the recognition of the other social formations as valuable in their own right” (Eckert, 2016, p. 242). These “ghosts” are called forth by evoking, through ethnographic writing, a kind of “awe of alterity,” which, by emphasizing human difference, can lead to understandings of difference as static and essentialist. According to Eckert, the task of recognizing and making space for difference without constructing difference as “all-encompassing” requires exploring commonality, advocating for recognition of difference, and making explicit the societal processes that construct difference. Such a task is necessary, as “our different ways of perceiving and conceptualizing the world are inflected by the relations of inequality in which we stand towards each other” (Eckert, 2016).

In Indigenous pedagogy, research, and theory, relationality is commonly applied as a concept to connote an ontological view that all beings are related to one another, the landscape, and spiritual world (Deloria, 1969). Barlow and Reading identify relationality as an Indigenous ontology of care in their research conducted for the Canadian Aboriginal AIDS Network (Barlow & Reading, 2008). Claiming that relationality is a

common theme shared across diverse Indigenous groups across North America, they described relational care as rooted in “connection, the link between all living things” (Barlow & Reading, 2008, p. 45). As such, relationality as a mode of care recognizes the responsibility inherent between those caring for and being cared for, through the gift of accompanying someone on a health journey or through end of life.

Taking a similar approach, Shawn Wilson (2008), an Opaskwayak Cree scholar, outlines relationality as a widely shared Indigenous world view and epistemology that can be used to inform Indigenous research methodologies. As such, relationality offers not just a metaphorical framework for gathering knowledge, but an ontology, a way of being and acting in the world. Wilson describes relationality as implicating accountability to relationships, but this accountability is not an ethical choice but rather implicated in the nature of reality. Wilson offers an illustrative visualization, the self as constructed by webs of relationships, that connect to and give form to others: human, animal, animate and inanimate:

...the relationships come to you from the past, from the present, and from your future. This is what surrounds us, and what forms us, our world, our cosmos and reality. We could not *be* without *being in relationship* with everything that surrounds us and is within us (Wilson, 2008, p. 76).

On a metalevel, the concept of relationality is applied in different contexts to describe or translate amenable ontological perspectives. In philosophy, relationality explores understandings of self, other, and the world around us as constituted in relationships. As extended to anthropology, how we understand and perceive human difference is embedded in relationships between the self and other, or at a macro level, the “us” and “them.” In Indigenous research, relationality is used to connote a worldview centered

around interconnection and relatedness. What these diverse applications share is that relationality is simultaneously ontological and ethical. In a relational ontology we are implicated beings—with others, our social contexts and environments as well as to powers unseen. As I will demonstrate, such a perspective allows for an examination of the co-existence and imbrication of social exclusion and relational care, as well as biomedical and Indigenous approaches to healing. I will apply relationality as both etic (as an ontological stance) and emic (as a descriptive of how care is or should be in a Nuuchah-nulth context) frames of reference. In doing so, I recognize that while every site of care – whether on a hospital bed or a community lunch – is framed by specific historical, political, and material processes as well as social constructions of difference, none of these sites and structures of care can be understood in isolation.

Care

In investigating the complex intricacies of working to improve access to health care within Nuuchah-nulth communities, I have framed my analysis around the networks of care that bring together diverse stakeholders such as health professionals and administration from the NTC and regional health authority, community members, healers, community health representatives and first responders. By investigating care, this shift in the object of analysis allows for a study of “practices in their immediacy rather than cultures in their atemporality” (Rabinow, 2007, p. 111).

Anthropologist John Borneman has asserted that care, as a “voluntary affiliation”, offers a crucial object of analysis for anthropologists. He argues that as anthropologists analyze other forms of affiliation (such as marriage, kinship, or gender), the assumption that these affiliations are present throughout humanity works to essentialize what we

come to understand as acceptable forms of affiliation. Contrary to this, observing “processes of caring and being cared for” (Borneman, 2010, p. 574) offers a way of gaining insight into how people organize their affiliation and actions in a less deterministic way. However, for my purposes I would suggest it is also important to inquire about the obligatory elements of care, especially in the case that it may be one’s occupation as a physician or healer.

Borneman draws from Heidegger who describes care as the existential foundation of being, as oriented towards potentiality, in the sense that “being-together-with” things or others is to take care of them. For Heidegger, temporality and human experience is founded in “the dialectic of coming to be, of having been and making present [... through which individuals] plot experiential sequences in narratives organized around that about which they care” (Borneman, 2010, p. 582). However, the process of taking care can limit the field of possibility by ‘leveling down’ to what is available at hand in an every-day manner¹⁰ (Heidegger, 1953, p. 186). The affiliations we form through the process of caring for one another informs our relations to one another, our subjective understandings of self, and guides the decisions we make. Similar to Robbins’ call to investigate “the way people understand the good and define its proper pursuit” (Robbins, 2013, p. 457), what is aspired to through this process gives shape to social actions and potentiality.

¹⁰ Having these theoretical insights on hand, it is important to note that the root of this conception is in Western philosophy. Heidegger draws on a Fable of Hygnius, an early Latin author, to illustrate the historical genealogy of the notion of care as the existential foundation of humanity (Heidegger, 1953, p. 191). However, the fable also reveals that such a notion is tied to other ontological formulations such as a spirit-body and nature-human dualisms that have been demonstrated as differently configured in other world views (Ingold, 2011; Nadasdy, 2007). Thus it is important to note that while care may offer an insightful object of analysis, the research process must remain open to different interpretations of care and its role in defining the nature of being in various cultural contexts.

In recent ethnographies, care is commonly addressed as something that cannot be defined *a priori*, as it can be enacted in infinitely multiple ways – though it may be subjected to material, social, and political constraints. For instance, in her ethnography, *Life in Debt*, Clara Han approaches care as a problem of daily life. Rather than being a given, under the precarious circumstances of impoverished Chilean families, the care for relatives and neighbours is something that is constantly negotiated. For Han, when and how to care for family members is an ongoing process of negotiation when resources are scarce and it is through this process of mediating care and defining its limits that moral obligations to others can be forged or in some cases abandoned (Han, 2012).

Anthropologist Lisa Stevenson also approaches care as a relationship and the articulation of moral obligations in her ethnography *Life Beside Itself* (2014). Similar to the approach outlined by Stevenson, I identify care as both the bureaucratic, institutional apparatus of health care, as well as everyday forms of care enacted in Indigenous communities. In her approach, care is nuanced as

the way someone comes to matter and the corresponding ethics of attending to the other who matters. Shifting our understanding of care away from its frequent associations with either good intentions, positive outcomes, or sentimental responses to suffering allows us to nuance the discourse on care so that both the ambivalence of our desires and the messiness of our attempts to care can come into view (Stevenson, 2014, p. 3).

Stevenson's approach allows for the possibility of different ways of attending to those who matter; to care in different ways, and, in the case of her work, to the possibility of caring indifferently. Stevenson's approach diverges from Han's in the sense that, rather than exploring how moral obligations emerge through processes of caring, she illustrates

how different logics of care can conflict in practice, by illuminating how bureaucratic forms of care are experienced as oppressive and even murderous in Inuit communities.

This conceptualization of care as subjected to a set of material, political and social limitations which works to exclude certain individuals is a common way anthropologists frame the concept, especially in the context of state or international institutions of care (see, for instance, Farmer, 2003; Fassin, 2007; Povinelli, 2011; Ticktin, 2011). For instance, Miriam Ticktin discusses how regimes of care operating within humanitarian organizations conceptualize refugees as patients to be cared for rather than as citizens. This conceptualization has influenced French immigration policy in the sense that only those refugees who are in the direst states of health are granted asylum (Ticktin, 2011). Fassin has described how images of marginalization form the moral sentiments which fuel humanitarian interventions, directing care only to the patients perceived as the most morally deserving by appearing to be the most destitute, while excluding from their programs less visible instances of illness (Fassin, 2012).

In viewing care as ‘the way someone comes to matter’ to others, I attend to processes of care as something that emerge through practice and therefore irreducible to any single logic or form. Such a perspective allows for the analysis of the negotiation between multiple modes of care. Importantly, by applying this understanding to the approaches I have outlined above which view care as not only the creation or maintenance of social relationships but also the articulation of moral obligations, such an analysis can reveal how different modes of care constitute different moral obligations and ethics. As care is subject to material constraints, it illuminates a site of negotiation between contending with what is at hand (such as a lack of health funding or

discrimination in local hospitals) and working towards what has been in the past and what could be (such as culturally safe healthcare informed by Nuuchahnulth *hahuupa*; teachings).

Though a means of theorizing suffering is necessary to this project, I also believe it is fruitful to take account of how historical trauma can be transformed through community-based forms of care, how exclusionary care and discrimination become normalized in institutional health services, or how Indigenous modes of care are transforming individuals' healing journeys as well as standard practice in health care broadly. This approach is made possible by remaining attuned to the interconnections of networks of care across every healing journey, rather than bounding analysis within the limiting binary categories of dominant-suppressed, Indigenous-western, or biomedicine-folk medicine. An ethnography of care shifts the focus from abstracted knowledge about health and how healing happens to how patients are attended to and the materiality of their experiences.

Evocative Ethnography

There are a number of means through which an ethnography of care can be analyzed. Care can be examined ontologically, as constituting realities (Cruikshank, 2005; Mol, 2002); as epistemic, containing a body of knowledge about health and healing (Martin-Hill 2008; Watson and Huntington 2008); ethical, enacting obligations, or even affective. In fact, though these various approaches connote different "turns" in the discipline of anthropology, I find it artificial to separate them. In my own work, I am most interested in the affective dimensions of care and how these forces actualize in the constitutions of ethics or moral obligations.

By looking at the affective dimensions, I am interested in felt experience – both my own as well as experiences described by project contributors. I understand affect as the bodily intensities or sensations that form an embodied response to the things, events, surroundings, thoughts and influences we encounter collectively as we move through the world. To affect or to be affected connotes the shift from one experiential state to another, reducing or contributing to bodily inertia, or our capacity to act (Deleuze, 1987).

An ongoing debate in affect theory is the degree to which we may contrast affect with emotion. Following the work of Massumi (2002), affect is understood as the intensities that activate us whereas emotion is fixed through cultural discourse and influences that shape subjectivities (Massumi, 2002). Emotion represents a socially and culturally shaped expression and requires a self-aware subject, whereas affect is a biological response and does not require a subject (White, 2017). However, other lineages of affect theory do not make the same distinction. In the 1980s, feminist theorists contributed to “a fundamental critique of the place of emotion in our everyday lives and the way in which affect works to inform and inspire action” (Gorton, 2007, p. 345). Around the same time, Indigenous writers were actively reframing colonial dominant narratives, and producing a kind of political witnessing that linked in with the rise of human rights discourses in the 1990s¹¹. These authors were “creating new language for communities to address the real multilayered facets of their histories and concerns by insisting on the inclusion of our lived experience, rich with emotional knowledges, of what pain and grief and hope meant or mean now in our pasts and futures” (Million,

¹¹ For example, Campbell 1983; Armstrong 1993; Maracle 1990; Campbell 1992, among others.

2013, p. 57). Queer theorists have also built on and expanded the work of feminist scholars on emotion and affect, by focusing on how emotion and affect link the individual or private with the collective and public. Affect has also been analyzed in relation to social structures, focusing on the ways in which ‘contagious feelings’ are transmitted (Gorton, 2007)

For instance, Sara Ahmed argues that the separation between emotion and affect undermines the ways in which unconscious experience is still mediated by past experience. Ahmed is critical of the assumption of unmediated bodily sensations, stating that “even seeming direct responses actually evoke past histories, and that this process bypasses consciousness, through bodily memories” (Ahmed, 2004, p. 39). Ahmed claims that the separation between emotion and affect is a purely analytic construct. I suspect the distinction between affect and emotion was developed as a means of theorizing feelings while retaining “objectivity” by announcing that a subject is not required for affect to take place. Such a stance works to undermine the effort of Indigenous, feminist, and queer scholars in highlighting the relevance of theorizing emotion¹².

For Ahmed, emotions are not something that we have, but rather they constitute how we relate to others. She states that “emotions create the very effect of the surfaces and boundaries that allow us to distinguish an inside and an outside in the first place”

¹² This conversation also relates to epistemic colonialism and the systematic devaluing of Indigenous thought. Indigenous knowledge is often described as acquired through the senses and intuition as well as intellect. In this way, dominant paradigms have dismissed Indigenous knowledge under the assumption that “emotions and motives must be removed if the research ‘results’ are to be valid” (Wilson, 2008, p. 56). Eber Hampton, a Chickasaw scholar, points out that all scholars conduct research for emotional reasons; there is something that drives us which is also connected to our intellect. He states, “humans—feeling, living, breathing, thinking humans—do research. When we try to cut ourselves off at the neck and pretend an objectivity that does not exist in the human world, we become dangerous, to ourselves first, and then to the people around us” (Hampton, 1995, p. 52).

(Ahmed, 2014, p. 10). These surfaces (between you and I, us and them, intimate and public, individual and collective) are produced through the impressions left by others. Ahmed's configuration of affect works with a relational framework, as emotions "involve (re)actions or relations of 'towardness' or 'awayness' in relation to such objects" (Ahmed, 2014, p. 8). Through the impressions left or received, emotions "work, in concrete and particular ways, to mediate the relationship between the psychic and the social, and between the individual and the collective" (Ahmed, 2004, p. 27). Emotions move us by bringing into focus the surface of encounters with others, reaffirming our attachments such as what connects us or what makes us different.

These responses to the world of others are always mediated through the readings of encounters in which emotions come to be seen as caused by a person or object. For example, racist or xenophobic sentiments expressed through speech or action reproduce hate towards racialized others as a threat to the togetherness shared between those seen as composing the "we" (for example, white nationalists) (Ahmed, 2014). Emotional intensities are an essential part of how social structures are formed, thus affect produces material consequences. Emotions can produce "investments in social norms" (p. 56) or ultimately provide a "form of cultural politics or world making" (Ahmed, 2014, p. 12). However, that is not to imply that, in the case of my own research, patients seeking health care are passive recipients of the affect produced through health care encounters. Here, I draw from Raymond Williams' structure of feeling to identify that different ways of thinking and experiencing health care encounters are continually vying to emerge as new discourses (Williams, 1961). Thus, through affect I acknowledge the moments when what

is most at stake is brought to the surface yet may not be fully articulated consciously but may correspond with a trajectory for social action.

I am interested in the transformative power of affect (Million, 2013), where affect can be imperceptible, or it can ignite mobilization. In this sense, affect, though experienced on an individual level, operates intersubjectively. What I find compelling about the “affective turn” is that “the point of analysis was not to track the predetermined *effects* of abstract logics and structures but, rather, to compose a register of the lived *affects* of the things that took place in a social-aesthetic-material-political worlding” (Stewart, 2017, p. 193). I find affect to be compatible with a relational ontology, in the sense that it offers a means to analyze interconnections. Viewing “the empirical as compositional” expands the “idealist paradigm that imagines the things of the world as a direct reflection of abstracted categorical distinctions” (Stewart, 2017, p. 197). There is a historical tendency within social theory to view emotion as irrational and contaminating of scientific objectivity, which has ignored the “sensory of the intersubjective realm, making it susceptible to abstraction, reification, and fetishization, and opening it up to reductive explanations of the social” (Skoggard & Waterston, 2015, p. 110). This same tendency has marginalized feminist and Indigenous contributions to “felt theory” (Million, 2013), which I draw on in addressing the different ways care manifests through Indigenous-settler relations in health care.

This is significant, as these same tendencies and scientific approaches are what underlie colonial anthropology, which sought to produce images of the noble savage for European consumption. In this sense, I find that affect theory is compatible with Indigenous paradigms that view emotion and intuition as sources of knowledge (Battiste

& Henderson, 2000; Million, 2013; Wilson, 2008). For instance, Athabascan scholar Dian Million uses affect theory to discuss the articulation of residential school experiences by Indigenous activists. She explains that due to experiences of isolation, denial, and the violation of their bodies, “the residents’ lives were fraught with a negotiation of their felt profaned status charging all their relations” (Million, 2013, p. 49). Attention to affect can reveal the lingering impacts of trauma or how modes of care can be experienced as exclusionary. However, it can also reveal the transformative potential of collective efforts to heal, or the impact of relational modes of care.

Theorizing affect requires what Skoggard and Waterson describe as “an integration of abstraction and illustration” or “evocative ethnography” (Skoggard & Waterston, 2015, p. 111). In my work, I describe affect as an embodied force that affords weight to moments; I write about the times when affect becomes palpable. However I am not interested in unnecessarily obscuring the social worlds I encountered, or evoking “the presence of some rarified substance called Affect” (Probyn, 2010). I am more interested in producing an evocative ethnography, through both abstraction and illustration, to offer some means through which readers can sense what I saw and felt, and through my writing and the words shared by research contributors, come to understand a little bit more about what it is to live with barriers to accessing health care in Nuuchah-nulth communities.

Conclusion

In my writing I aim to create space for multiple meanings. Some of the concepts I explore, such as cultural safety, tend to take on their own lives, whether prescribed in policy, put into practice by nurses, or as they are taken up colloquially in communities. While people may be exchanging the same concepts through conversation, they can be

understood in different ways. Similarly, I write about “modes of care” as I view care as multiple because of the ways in which it is put into practice; it offers a potentiality rather than a definitive, unitary, and abstracted ideal (Mol, 2002, 2008). Through the socio-cultural meanings ascribed to health care experiences, I am interested in how health inequity has come to be, how it continues to affect health care experiences and access to health care, and how it is transformed through the assertion of Indigenous approaches to health care. In the following chapters, this thesis explores the networks of care, multifaceted layers of health administration, and the negotiation between different modes of care through a critical application of Indigenous-relational theory, affect, and biopower. I bring together these diverse theoretical traditions as a means of thinking through the coexistence of social suffering and spaces of hope: the ongoing structural racism in health care services and the relational care that mitigates health inequities, informs hope, reinvigorates Indigenous culture, and transcends biomedical configurations of care.

I am also committed to producing work that is relevant and meaningful for the communities and organizations with whom I worked. In this sense, my fieldwork and analysis are largely shaped by objectives that have been identified through collaboration with the Nuuchahnulth Tribal Council. These objectives include identifying opportunities and challenges between cultural safety as a policy mandate and the on-the-ground delivery of responsive and respectful care in Indigenous communities. Additionally, an objective is to produce experiential data on opportunities and barriers to accessing culturally safe care in Nuuchahnulth communities. I position myself as an observer of the process of increasing access to health care, maintaining a critical stance

towards the politics of recognition and institutionalized forms of health care that have historically been linked to processes of colonial domination. Ultimately, my hope is that these findings bring to light the social, political, and jurisdictional barriers to providing health care – rather than blaming poverty, remoteness or lack of capacity, as is often done in public discourse – to demonstrates the spirit of survivance (Vizenor, 1999) that motivates the pursuit of better standards of health care through self-determination.

The following chapter, Chapter Two, provides an outline of my methodological approach, describing a decolonial and collaborative stance to working with stories to produce knowledge about shared experiences of health inequity and the collective and relational forms of care that mitigate and transform these experiences. Chapter 3 discusses the relationship between Indigenous governance, or self-determination over health services, and the provision of culturally safe or relational care. It describes how through the NTC nursing framework the nursing staff effect a kind of relational care which has had profound implications for community well-being. Chapter Four addresses the lack of access to health care services in remote communities, describing health inequity as a structural violence forged in the colonial history of Canadian health services, and normalized through implicit settler colonial assumptions about “remote” living. Chapter Five looks directly at experiences of anti-Indigenous racism in health care services by examining how discrimination constitutes healthcare experiences and the normalization of discriminatory attitudes and practices in health care. As a manifestation of systemic and intersubjective dynamics, seemingly innocuous practices can inflict harm through implicit racialized assumptions. Chapter Six explores the affective and ontological dimensions of informal care in Nuuchahnulth communities to understand

care as a collective phenomenon. Lastly, Chapter Seven examines the intersections between the NTC nursing framework and biomedical standards of care, understood through the politics of liberal cultural recognition, to show how the indeterminacy of biomedicine and recognition enables the persistence of alternative social projects, which are shaping conversations on the ethics of care. Ultimately, “mainstream” medicine is both profoundly influenced by and resistant to Indigenous healing and approaches to care. At the same time that biomedical standards and institutions fail Indigenous communities and suppress Indigenous approaches to healing, these same standards and institutions are being transformed by the resurgence of Indigenous approaches to healing and the assertion of relational care.

Chapter 2: Methodology

Eight months into fieldwork, I was listening to a conversation between NTC staff and First Nations health directors about the possible merits and dangers of increasing research in Nuu-chah-nulth communities. A Health Director explained that “our people would say anything to get the interviewers to leave. So what is written in the books isn’t even true” (personal communication, May 31, 2018). This comment made my face flush with shame and I felt a sort of sharp sting in my chest. I did not want to be one of those researchers! But comments such as these are also gifts; the affect they stir in us allows our pathways to become much clearer. A pathway that was reaffirmed for me in this moment was that of decolonization.

Through this story, I take an opportunity to position myself in support of Indigenous self-determination of health services. This work is motivated by my own ethical commitments including challenging inequity and discrimination and empowering alternative modes of healing and care giving. This work is informed by the imperative to explore the social and political dimensions of access to health care, or how access is tied to colonial power structures. My skepticism of the limits of care in biomedical contexts in a large way fuels my interest in this work and likely has contributed to my rapport with the communities I have worked with. Working on this project has expanded my awareness that many of the answers to shortcomings within public health can be found in Indigenous teachings. My reverence for these teachings implored me to do what I could

to better understand what they meant for me as a researcher and to embody them in my own work.

I am interested in the local moral worlds (Das, 2015) that are produced via care. Local moral worlds are spaces of experience where what is most at stake for people is made explicit (Das & Kleinman, 2001). These moral worlds are generated through the myriad affects produced through processes of care. I trace some of these affects by exploring divergent modes of care in Nuuchahnulth communities, including abandonment or exclusion, grief, connection, and hope. I draw from critical medical anthropology to trace the modes of care that perpetuate inequity, for example how the designation of “remote” is a colonial construction that justifies substandard health services, or the norms and practices that perpetuate racism in clinics and hospitals in the form of implicit bias. I also examine care through an Indigenous relational lens, which brings to light—through our embeddedness ethically with the others around us—the inadequacies of care that is configured as a financial transaction, or a temporally limited association. Similarly, by looking at the relational affects produced through the Nuuchahnulth nursing approach, I make visible how this locally produced mode of care works with dominant biomedical care practices to increase access to health services. I draw on these diverse examples to demonstrate how cultural safety is produced in the context of colonial health inequity and the impact of these tensions on Indigenous communities.

In the field, I discovered that healing happens across many diverse sites; in health clinics and hospitals, in community clinics, family homes, and in community gathering spaces. For this reason, the methodology I applied involved a multi-levelled analysis of

the intersection between these various sites and the political-structural aspects of health care provision by examining the narrative accounts of caregiving experiences held by NTC nurses, clients, community leaders, and Elders, as well as participant observation obtained during nursing visits, health-related workshops, and community events. In this chapter, I outline a decolonial methodology, how collaborative ethnography informed my approach, and how data was analyzed through an iterative interpretative thematic method informed by Indigenous research methods.

Methodological Approach

Anthropology emerged as a discipline through the encroachment of colonialism across the globe. The discipline's professed role in speaking on behalf of the newly colonized peoples was "accorded with the imperatives of Empire and in this, specific technologies of rule that sought to obtain space and resources, to define and know the difference that it constructed in those spaces, and to govern those within" (Simpson, 2007, p. 67). Though early anthropologists attempted to distance themselves from the colonial processes of conquering and 'civilizing' by emphasizing the intrinsic value of diverse cultures, their work tended to construct Eurocentric representations of Indigenous cultures as primitive, exotic, or locked in the past (Deloria, 1969; D. Smith et al., 2006). It is pertinent to take account of this history, as colonialism continues as an ongoing process, and is not solely limited to historical events (Alfred & Corntassel, 2005; Wolfe, 2006). As anthropologists, to fail to situate ourselves in relation to this history is to perpetuate the complicity. Indeed, research continues to be experienced as oppression in Indigenous communities, "through the use of culturally insensitive research designs and methodologies that fail to match the needs, customs, and standards of Indigenous peoples and communities"

(Cochran et al., 2008, p. 22). However, awareness only takes us so far. In order to bring an end to complicity with cultural imperialism, decolonization must be embedded into our practices throughout the research process.

Decolonization implores researchers to produce knowledge about colonialism and the experiences of Indigenous peoples from outside a Western hegemonic intellectual tradition. According to Maori scholar Linda Tuhiwai Smith, any theory originating in Western thought—even despite aims to promote equality or to empower Indigenous voices—finds its roots in the same rational-scientific and humanist logic that was used to justify colonial oppression (Smith, 1999). As long as theory about Indigenous peoples is generated within Western modes of thought, the authority to define who and what Indigenous People are will remain with Western scholars, thus replicating the division between academic interests and community-based understandings. Smith suggests that developing social theory through Indigenous epistemology offers a route to legitimizing Indigenous experiences, strategizing resistance, and recognizing Indigenous Peoples as key stakeholders in contemporary global politics and economy (Smith, 1999). Through developing Indigenous theory, new research methodologies, theoretical paradigms and writing modes have been developed, which more concretely and accurately represent Indigenous perspectives and speak to Indigenous concerns (Archibald, 2008; Kovach, 2009; Loppie, 2007; Wilson, 2008).

The ability to “understand from an insider point of view” is likely the most overlooked colonial assumption in anthropology. There is certainly some merit to the commitment to understand knowledges, practices, and beliefs as situated within a specific historical, political, socio-cultural, and/or geographical context—in bringing awareness to

the variations and commonality of human experience. But there is an inherent power imbalance within the assumption that anthropologists are capable of getting at that deeper understanding, and, in extension, have the authority to speak on behalf of others.

The limits of our knowledge are made most obvious while conducting fieldwork, while we are in conversation and living the connections we have built with the people we work with. As part of my decolonial approach, I try to reflect on the moments when my lack of understanding was made apparent to me, in the hopes that my work remains humble. For example, at an event to kick off a new long-term health research project organized by the NTC, I had brought my daughter with me to the evening events. My daughter enjoyed the singing and drumming, and especially the food. But with the excitement of the festivities, it was difficult for her to keep still. The dining tables were adorned with red tablecloths and cedar boughs. My daughter kept picking up the boughs and swinging them around during dinner. As mothers do, I barked an automatic command to settle down; “leave that there, it is meant for decoration.” An Ahousaht Elder who was sitting near us, overheard me and immediately corrected that the cedar was *not* a decoration. He stood up and shared about how for the Nuu-chah-nulth, cedar is very powerful and was laid on the tables as a form of protection. When female dancers open events, holding cedar, the motions of their dancing with the boughs works to deflect negative energy, thereby protecting the other performers (Field notes, May 31, 2018). In this moment, both my daughter and I were presented with an opportunity to learn about manners.

Through this story, I acknowledge that my learning was not and is not complete. I must continue to carry forward a decolonizing approach, by refusing to take an

authoritative stance on Nuu-chah-nulth culture or identity and by using my position as a researcher to advance community interests rather than inadvertently shifting attention towards what is deemed valuable from an external perspective. My attempt at doing so involves thinking through Indigenous research methodologies, aligning the object of this study with goals identified by the NTC, and applying a collaborative approach.

Centering Indigenous theory can support a decolonial objective by grounding analysis in community perspectives. As a non-Indigenous scholar, my aim is to centre Indigenous epistemology in my work, and to make explicit that I am striving to learn from and think through the works of Indigenous scholars and the teachings of Nuu-chah-nulth knowledge keepers. Yet I also recognize that I cannot claim to be an expert in these ways of knowing. In thinking through Indigenous research methods, I draw again from Atleo, who highlights *hishook-ish tsa'walk* as an Indigenous theory which recognizes spirituality, faith, intuition, and emotion as sources of knowledge. In his writing, stories are a key mode through which the “foundation of knowledge about the state of existence” (Atleo, 2004, p. xi) is obtained, as well as a framework for interpretation. Through *hishook-ish tsa'walk*, the unity between the spiritual and physical realms of existence reveals knowledge as existing in the relationship between variables. Similarly, Nêhiyaw and Saulteaux scholar, Margaret Kovach, describes Indigenous research methodologies as founded on a relational world view in which observation and direct experience are key to holistic knowledge acquisition (Kovach, 2009, p. 34). This process also involves interpretive and reflexive work by exploring one’s own motivations and process of discovery and learning. In my approach to research, I draw on Kovach’s insight that elevating the acceptability of Indigenous methods within academia allows us to honour

Indigenous knowledge systems, support cultural longevity, disrupt homogeneity within academia, offer a more ethically driven way to produce knowledge, and reduce “methodological discrimination” wherein Indigenous research methods are not seen as a viable option for research.

My approach is to consider how anthropologists frame and position themselves toward an object of study throughout the research process. I assert that attending to the dynamics of this relationship is an effective way of addressing how power relations impact the types of interpretations we construct. I am not interested in producing an objectified account of Indigenous healing as it is not my place to speak authoritatively on these matters. Rather I focus on the tensions and transformations occurring where multiple modes of care such as NTC relational nursing practices and biomedical standards confront. By focusing on the interactions between diverse stakeholders and the networks of practice that bring them together, my approach attends more directly to the complex ways in which structures of power, such as the authority of medical expertise or entrenched paternalistic colonialism, impact access to health care and the process of healing.

Kovach states that in an Indigenous epistemology, “validity is bound with giving back to community, which is integral to ethical research” (Kovach, 2009, p. 149). By giving back, we must question for whom the research is most relevant. Giving back goes beyond disseminating findings with the people who contributed and includes building an ongoing relationship throughout the research process. Researchers are implicated with the communities they work with (i.e., by producing knowledge that affects them). An Indigenous perspective makes this explicit by tying the validity of a project to ethical

obligations to those involved. Kovach describes this as a relational research approach. This is similar to Wilson's relational accountability which obligates researchers working under an Indigenous methodology to the organizations and communities they work with. Indigenous research ethics are also relational in the sense that obligations are contextually constituted, grounded in cultural protocol and the shared needs and aspirations within communities (Thomas, 2015). My aim is to "give back" by producing evidence to support advocacy and awareness of the import of the NTC nursing approach and to uncover the hidden assumptions that normalize health inequity and perpetuate racism in health care, as these were priorities identified when developing this project with the NTC.

Indigenous scholars have highlighted how decolonization operates as an ongoing practice, because ethics are activated through how we live our lives (Archibald, 2008; Kovach, 2009; Thomas, 2015; Wilson, 2008). I take this to heart in the sense that with the forms of care and resistance I describe, I also attempt to integrate these into how I conducted research and described my findings. So, I write about processes of decolonization by taking a decolonial approach, I talk about relational care through a relational worldview, and I asked questions about cultural safety using a culturally safe interview approach. I think part of my contribution is not just to describe processes of decolonization and healing, but to carry them forward through an effort to embody them in how I write about them. A related goal is to consider how settler accomplices can take up Indigenous theory in ways that are productive rather than appropriative, diminishing, or extractive. I do not portend to have a solution, but these are the concerns I continually respond to. A commitment to decolonization and collaboration also underlies the theoretical choices informing this project. As several Indigenous mentors have

encouraged me, there is work for settler accomplices, we just have to do the work of self-incrimination to figure out what that job should be. As such, I have committed to not getting comfortable, to constantly questioning the impact of my work, and to remain open to criticism from research participants as this is foundational to dismantling colonial power hierarchies in research.

Research Design

This research was conducted under a collaborative research agreement with the NTC. A collaborative approach ensures joint ownership of data and ongoing dialogue with participants about the direction of research, analysis of findings, and how findings will be shared (Lassiter, 2000). Collaborative ethnography is an approach to aligning research design and outcomes with community goals. It requires the relinquishing not only of authority over representations but also expectations for the outcome of the work, as participants in the fieldwork give form and meaning to the work (Lassiter, 2000). Beyond representing the co-construction of knowledge, collaborative ethnography actively seeks input and verification by research partners, ensuring that perspectives and experiences are accurately represented.

As directed by the NTC, this project was supervised by management in the NTC Health Department. Prior to beginning fieldwork, I attended a pre-fieldwork visit and was shown the NTC head office and introduced to nursing staff. I also accompanied some of the nursing staff on a trip to the northernmost community, Kyuquot. Concluding the visit, I discussed with nursing management about the project scope, focus, and approach. Key concerns voiced by the NTC involved shifting focus from looking at the interaction between Indigenous and biomedical healing approaches to looking at the interaction

between health systems and the barriers nurses and communities face in connecting community members with needed health services. There was also an emphasis expressed on taking a “culturally safe” approach to research, which involved spending time in communities, attending community events, working inductively to allow participants to direct conversations, and being available and taking time to spend with participants rather than enforcing an external research agenda. Taking an inductive approach and guidance from research partners at the NTC, the research question was adapted slightly to focus more specifically on the concept of cultural safety and how this idea is defined, experienced or practiced within Nuuchahnulth communities, the NTC nursing services, and regional health policy. Fieldwork took place between September 2017 to August 2019. During this time, I was supervised by NTC nurse manager and submitted regular reports. NTC nursing staff assisted with recruitment and connecting with key informants by formally introducing me and the project at numerous community events or sharing project information with clients. I also provided research consulting to the NTC in support of external projects, including grant and research agreement writing, developing ethics protocols, and providing research skills training.

At the commencement of the research project, I was invited to a Health Directors meeting. The NTC Health Director presented the project scope and objectives to the group and the health leaders from each of the attending Nations offered feedback, suggestions and expressed their level of interest. It was an interesting experience because rather than feeling put on the spot, there was a thoughtful and balanced conversation, revealing an investment in the project and what was seen as its merits. It felt as if the project had collective ownership. Key concerns raised were that communities are already

“researched to death”; that remote communities are underrepresented in current health data; and concern over what will happen to participants’ stories once recorded. These concerns were addressed through recommendations suggested by health leaders.

According to Simon Read, the NTC Health Director at the time, the merit of the project was to answer the question, “why cultural safety?” ultimately as way of advocating for the NTC nursing approach.

Throughout my time at the NTC, I met with nursing management periodically to discuss emerging findings, the progress of my field work (what communities I had visited, which nurses I travelled with, how many interviews I was conducting) and to strategize on how to expand participation and community visits. I found these meetings very encouraging and helpful, although on occasion my ideas would be challenged. Similarly, recruitment for the project was entirely collaborative. Nurses and community health leaders described the topic and objectives in their own words or introduced me and my work, and in that way the project took on its own social life. The new insights I gained from others via conversation about the project have left a significant impression on this work.

During my fieldwork, I was afforded an office space at the NTC head office. Initially, all the contacts I made with health leadership, NTC clients, and Elders were made through the NTC nursing staff. I was firmly encouraged by management at the NTC nursing services to spend my workdays (when I was not traveling or conducting interviews) at the NTC head office, and was provided with a desk, chair, and phone in the storage room in the nursing department. I shared this space with spare furniture, bookcases and shelves with tubs of health education materials, medical supplies,

syringes, a scale, and naloxone kits. The storage room is located in a corner office with two windows looking out over the parking area. Outside my window, I could see people coming and going to the office or setting up for community events. My favorite days were when folks would arrive with large box-shaped crates of fresh seafood being redistributed to community members, who were already lining up with iced coolers in hand.

Participant Observation

My approach to participant observation departs slightly from the more traditional configuration of a lone ethnographer remaining in one field site. My role at the NTC was both as a student ethnographer and as an embedded health systems researcher. In the latter capacity, I did research skills training workshops, wrote partnership agreements and project protocols, networked and drafted research grant proposals, facilitated or delivered talks on various topics, acted as project manager, research assistant, and liaised between research teams and community in support of the various research objectives ongoing at the NTC. Much of this work, I completed through the spirit of “giving back” or lending my skills in ways that were productive for the NTC and communities. At the same time, this role also facilitated building deeper connections with Nuu-chah-nulth leaders and communities and exposed me to experiences and teachings that have significantly informed my research and writing.

Another way that my approach departed from traditional ethnography was because of the misalignment between conducting a study of health care experiences, without necessarily being present to those experiences. Though *participant* observation is widely considered to be fundamental to ethnographic research, there are some contexts in

which anthropologists cannot engage as an active participant. An obvious example of this is within health care settings when the anthropologist has no training in the medical sciences. In terms of NTC nursing, I observed with moderate participation (as I interacted with participants who were aware of my research) during home visits with the NTC nurses and accompanied nurses during their travels to Nuuchahnulth communities. I travelled with the nursing staff during their community visits, including travel to Huu-ay-aht First Nation, Ehattesaht First Nation, Nuchatlaht First Nation, Kyuquot First Nation, Ditidaht First Nation, Tla-o-qui-aht First Nation, Hesquiaht First Nation, and Ucluelet First Nation. During some of these visits, I attended with nurses on home visits and met with clients while being seen by the nurses. In other cases, I spent my time at the community health clinics and observed the nurses' rapport with clients through casual interactions in the health clinics and spoke with individuals as they passed through the clinic throughout the day.

In Port Alberni, I frequently ate my lunches in the staff break room and was invited to office functions. Other events I attended in Port Alberni included NTC staff events (retirement parties, Christmas parties, send-off lunches, and impromptu "coffee breaks"); community healing events; and meetings related to additional research commitments (community consultations, planning meetings, and training workshops). Some of these projects included studies to improve nursing care in remote communities, a creative brokered dialogue project on cultural safety, the development of mobile screening clinics, and an Indigenous healthy life trajectories initiative. Additionally to these experiences in Port Alberni, I also spent a considerable amount of time travelling independently. During community visits, I spent my time hanging out at the health clinic

or community centres. I also attended (when invited) health fairs, town hall meetings organized to discuss key concerns, Elder's lunches, cultural nights, and community meals. I also spent my time visiting friends, although in these moments it becomes hard to disentangle research and personal life.

Because I was based at the NTC Head Office and engaged with all of the fourteen nations in recruiting for the project, there were a number of layers of consultations that had to occur both within the NTC and each of the First Nations. As such, I also connected with health leadership at each of the nation's individually before proceeding with recruitment. Due to the extensive travel required, my time spent within each of the communities was limited to a few days per visit. Had the project been situated within one particular community, I would have been provided with a very different perspective. However, through being situated in Port Alberni, I gained an in-depth understanding of how the NTC functions and relates to the member First Nations as well as the structure of the regional health system. I also benefited from invaluable mentorship from NTC management and staff.

Another constraint that I faced was balancing single parenthood with research. My daughter accompanied me on many of my community visits. In some cases, people were happy to help entertain her, and she developed friendships with some of the local children. In other cases, she interrupted interviews, caused sleepless nights, and had tantrums during travel. At community events she loved to dance to the drumming; in some cases, this was accepted adoringly, and in a few cases, we were scolded—some songs are not open for public participation and are meant only to be observed. I felt for the most part people were compassionate towards my responsibilities as a single parent,

however in one case a potential interviewee took offense at the fact that I had the “privilege to bring my kid to work with me.” A solution I found was registering her to multiple day cares. For example, the Ucluelet day care allowed me to drop her off occasionally when I was working on the west coast, whereas she regularly attended day care in Port Alberni. However, this practice was limiting in the sense that I had to arrange to travel in and out of communities on the same day before the day care closed. Despite these constraints, I also engaged in an extensive amount of travel independently. I was able to visit most of the Nuuchahnulth Nations at least twice. Of the 14 Nations, I was unable to visit Toquaht First Nation due to lack of interest or capacity to participate.

Figure 2: Travelling from Fair Harbour to Kyuquot, June 20, 2017

Narrative Interviews

My approach to interviewing was a narrative format by eliciting storytelling. In this sense, I draw from Indigenous theory on story (Archibald, 2008; Atleo, 2004; Cruikshank, 2005; Wilson, 2008). A narrative approach can support Indigenous research methods, as stories are widely recognized as a means for transmitting knowledge within Indigenous epistemologies (Atleo, 2004; Kovach, 2009). My aim was to reproduce stories verbatim, keeping the content intact while also bringing multiple stories into conversation with one another by compiling and arranging them in the context of this text. I share historian Laurie Meijer Drees sentiment that, “oral histories are more than answers to structured interview questions. They are instead a part of a person’s life – a little bit of personal energy – that must be handled with respect and care, and not simply turned into objects of study. Stories are gifts given, not collected” (Meijer Drees 2013, xxi). Story is a relational method, which retains implicit responsibility to protocol, ethics, and building trust (Kovach 2009). The receiving of stories also comes with responsibility—both the one who listened and compiled the stories and for the reader. In an Indigenous research methodology, listening and taking in offers a means of preparation for the resulting responsibility of affecting others when words are shared publicly (Archibald, 2008). This is an important consideration, as “the story teller’s responsibility toward others is linked to the power that his/her stories may have” (Archibald, 2008, p. 27). This affective power is rooted in the stories as they were told to me, and I aim to carry that forward as I relay them. Ultimately, storytelling offers a resistance to colonization; these stories “tell a counter-story to that of the documented history of Indigenous people in Canada” (Thomas, 2015, p. 183).

In many Indigenous traditions, stories contain a multiplicity of meaning (Archibald, 2008; Battiste & Henderson, 2000; Watson & Huntington, 2008). The sole authorship of this thesis condenses this complexity to my own interpretations. However, as Stó:lō scholar, Joanne Archibald has noted, stories continue to stay relevant after their telling, and “other meanings unfold in various contexts” (Archibald, 2008, p. 10) as we discover new meaning and insights from stories through our lived experiences. My hope is that this unfolding of meaning can be somewhat retained by keeping stories intact by using verbatim transcripts, recognizing that “no single interpretation can capture all their meanings” (Cruikshank, 2005, p. 53).

I conducted a total of 33 semi-structured interviews with NTC nursing staff, NTC clients, Elders¹³, and community health leaders. Interview topics explored key themes around how care is defined, how participants characterize their experiences of providing or seeking care, and what meanings they ascribe to these experiences, as well as the sites of disjuncture between expectations and how this is negotiated (see Appendix A). Of these interviews, 11 were with nurses (1 man, 10 women) and 22 were with community members and community health leaders (7 men, 14 women, and 1 conducted in a group format). Of the 22 interviews with community members, 12 of the respondents were recognized Elders. One of the interviews was conducted in a focus-group format during

¹³ It is my understanding that the individuals who are recognized as Elders in Nuuchahnulth community are those who have obtained a certain status as a knowledge keeper. Archibald describes a similar distinction in the Stó:lō context; “usually, wisdom is attributed only to Elders, but this is not because they have lived a long time. What one does with knowledge and the insight gained from knowledge are the criteria for being called an “Elder” (Archibald, 2008, p. 3).

an Elders' Gathering with the Elders of Tsaxana (Mowachaht/Muchalaht First Nation)¹⁴.

While these designations (nurse, client, community member) are helpful towards organizing interview data, they do not neatly represent the reality of NTC nursing or Nuu-chah-nulth communities. As mentioned in Chapter 1, some NTC nurses are Nuu-chah-nulth, some are Indigenous from another nation, and many have deep familial connections with Nuu-chah-nulth communities. The tension between belonging as an integral part of the community and not belonging (for those who were not born into the communities, or live away from home, or attempt to retain some professional distance while living and working in the same community) is something all nurses seem to negotiate in different ways. All participants have been provided with a pseudonym in the Nuu-chah-nulth language to reflect the complex ways different participants are related to Nuu-chah-nulth communities.

The nurse interviews were conducted at a location of their choice, typically within the health clinic they worked in or at a public location such as a café. The interviews conducted with NTC clients, community members, and Elders were also conducted at a location of their choice, typically either in an unused office in the health clinic in their community or in their home. The recruitment methods used to connect with NTC clients varied among the communities. In some cases, I was connected to knowledgeable community members by the NTC nurses or health leaders in the community. In other cases, I introduced the project during a community event. The duration of these

¹⁴ The Nations represented in the interview sample include Ucluelet (n=3) Kyuquot (n=1); Tseshah (n=1); Ahousah (n=3); Uchucklesah (n=4); Ehattesaht (n=3); Ditidaht (n=3); and Hesquiaht (n=1), as well as participants who identified as away from home Nuu-chah-nulth members (n=2).

interviews lasted between 30 minutes and 3 1/2 hours, with an average duration of 50 minutes. Twenty-four of the 33 interviews were audio-recorded; the others were recorded by notes as per the interviewee's preference. I provided participants with an interview guide to look at before starting but explained that it was only a guide to help us to get thinking, and that it did not matter if all questions were answered. I also clarified that I was interested in learning about what was most important to them, regardless of whether it was covered by one of the sample questions. Most participants skimmed the list and spoke to the questions that stood out to them. Not all questions were relevant for each participant, however I would often turn to the question list if it seemed the conversation had stalled. For the most part conversations flowed to and away from the question guide, while the conversation took on an unscripted, organic form. Often when visiting Elders, the stories began to flow before I had barely settled in, and I had the distinct impression they already knew what experiences or wisdom they wanted to share before I arrived for the interview. Transcripts were given to storytellers and they were asked to ensure that the transcripts were accurate, and to take the opportunity to change or add to what was recorded.

Analysis

Interview transcripts and fieldnotes have been analyzed following an iterative interpretative thematic method, leading to the generation of themes and semantic categories (Spradley, 1979). Coded excerpts from transcriptions and observational notes have been further categorized by the position of the speaker (i.e., as an Elder, health leader, nurse, community member, or a combination of these). These categories helped to

identify the speaker's position towards the topic at hand, as well as to recognize the authority attributed to Elders' contributions in terms of cultural knowledge. Some themes were only discussed by nurses and others only by community members; however, the majority of themes were addressed by both. Other sources of data included policy documents, local news reporting, and NTC nursing materials (including previous reports, surveys, frameworks, and training courses). During the coding process, transcripts were read for themes, anecdotes, or examples. Using cue cards, excerpts were then indexed under broad themes that had emerged from the initial coding process. These initial themes were revisited throughout the coding process to reflect emerging trends and identify sub-categories. Fieldnotes were then coded according to the themes that emerged from coding the interview transcripts.

Coding of transcripts was conducted during fieldwork and emerging themes were discussed with NTC nursing management during reporting meetings. An extensive codebook was developed indicating themes, subthemes, number of responses in each participant category, a brief overview of emerging findings pertaining to each theme, and a few examples. The data obtained through observation and semi-structured interviews were analyzed to articulate key themes around how nurses, community members, and administration define care, what characterizes experiences of seeking or providing care, and what meanings are ascribed to these experiences. Interview transcripts were read and re-coded numerous times to reflect emerging themes. Key findings emerging from the

stories¹⁵ have been triangulated with historical accounts, statistical information, and policy documents.

The Nuu-chah-nulth Patient Voices Project

During the second year of fieldwork, my attention shifted through an opportunity to more explicitly address the imperative of providing effective and dignified emergent¹⁶ and primary care to Indigenous communities, leading to the creation of the Nuu-chah-nulth Patient Voices Project. This project utilized storytelling and dialogue to address the systemic racism that persists within the health system and to provide a climate of trust between Indigenous communities and health care providers. It was initiated through a collaboration between the SE Health Care Research Centre, the Nuu-chah-nulth Tribal Council Nursing Services, Tseshah First Nation, and Mowachaht/Muchalaht First Nation. I was supported by a Health System Impact Fellowship through the Canadian Institutes of Health Research as the nominated principal applicant. In this role, I coordinated a research team consisting of health leaders from the Tseshah First Nation and Mowachaht/Muchalaht First Nation, the NTC, SE Health Care, and representatives from the regional divisions of family practice. This team was responsible for project design, planning, and networking with the Nuu-chah-nulth communities and health care providers as appropriate, throughout the process. This participatory research-to-action project aimed to build dialogue and increased understanding within local health systems around the importance of culturally safe health services for Indigenous communities and

¹⁵ I avoid paraphrasing, unless it is a similar statement that had been shared repeatedly by many participants. Dialogue is reproduced as close to the original telling as possible.

¹⁶ Emergent care refers urgent care requiring hospitalization or that poses a threat to life.

to identify actionable steps to enhancing cultural safety across health systems (including Indigenous nursing services, local hospitals, and family practice). Additionally, the objective was to enhance the continuity of culturally safe care at the interface between transferred Indigenous health services and provincial/regional health care providers on Vancouver Island.

The Nuu-chah-nulth Patient Voices Project resulted from extensive planning with participating First Nations and the NTC. Using a brokered dialogue (Parsons & Lavery, 2012) and Indigenous storywork (Archibald, 2008) methodology, the approach was to bring forth the experiences and stories of community members and health care providers about the impact of culturally safe or unsafe health care practices. The brokered dialogue methodology has been proven effective for addressing controversial health issues. Brokered dialogue (Parsons & Lavery 2012) is a film-based, creative methodology which focuses on perspective-taking and dialogue to address socially controversial issues. This methodology involves a process of a) developing an in-depth understanding of common positions on an issue, by producing a series of story videos, b) highlighting points of contention, by having participants view the story videos and share their reflections, c) indicating whether participants' perspectives have shifted over the course of dialogue, by eliciting reflections, and d) proposing solutions, both during the interview process by asking participants, as well as through later analysis (Parsons & Lavery, 2012).

Over the course of the project, a total of 11 First Nations community members and 13 health care providers participated in an interview. Evidence was generated through the brokered dialogue process, drawing on a semi-structured interview format captured through audio and/or video recording. With the help of a local videographer and

a member of the Quu'asa Team,¹⁷ I recorded community members' health care stories. Participants were asked to share stories of their health care experiences which expressed the importance of cultural safety, whether positive or negative encounters. I then met with local health care providers (family practice and emergent care), asking them to view the patient story videos that were collected. Health care providers were asked a series of questions, reflecting on their immediate impressions, key issues, what could have been done differently to improve the patients' experiences, and what they anticipate the impact of viewing the patient stories will have on their practice. I recorded the health care provider's responses and shared these with the community members whose stories they had responded to. Interview transcripts have been qualitatively analyzed by myself and members of the SE Health Care Research Centre, using a framework analysis for applied policy research (Gale et al., 2013; Srivastava & Thomson, 2009). The videos and findings from the storywork and brokered dialogue process will be used to develop, in collaboration with participants, educational resources to increase cultural safety awareness across health systems, determined collaboratively with the project partners based on community priorities, current needs, and findings from the brokered dialogue process.

Key findings from this work include evidence that discrimination, stereotyping and harmful assumptions are prevalent, especially in emergency rooms and walk-in clinics in the regions. Stereotyping often leads to misdiagnosis or a failure to investigate and treat critical conditions; for instance, by falsely assuming a patient's condition is

¹⁷ Quu'asa is a traditional healing program offered by the NTC Mental Health Services.

linked to alcohol use rather than an underlying medical condition. Patients also identified that experiences of poor care have profound emotional impacts which also affect physical health. A commitment to adopting a culturally safe approach within health systems, hospitals, and clinics is not enough to transform established discriminatory workplace cultures nor translate relational and supportive care into standard clinical practices. Additional efforts are required to redefine standards of care, which will require learning from Indigenous Elders, leaders, and patients. The Nuuchahnulth Patient Voices Project offered considerable insight and recommendations towards enhancing cultural safety from the perspective of Nuuchahnulth-aht, many of whom have been subject to, or a witness of, racism within health care. These recommendations have been presented to health decision makers at the regional and provincial level. My thinking has been significantly influenced by the insights gathered from the patient story interviews as well as from the doctors' commentary on the patient stories, particularly their thoughts on the root causes of discrimination in health care. In some places, I include interview transcript excerpts from the Nuuchahnulth Patient Voices Project that help to illustrate the themes and arguments I develop in this thesis.

A Note on the Mode of Writing

I draw on affect as a mode of transmitting information to readers, something I find is always present in ethnographic writing as anthropologists attempt to draw their readers into a specific place and time. However, rather than implicit, I deliberately aim to reconstruct my own affective positions. I do this for two reasons. The first is to convey to readers understandings that either cannot be described or accurately conveyed textually, and secondly, to situate the arguments proposed within my own experience and

interpretations, leaving space for multiple interpretations. I do not follow along a chronological recounting of my field experiences in my writing. Embodying a decolonizing approach, my aim is to contest the tendency of writing in the ethnographic present as an authoritative account of how things are in a specific social setting (Brodkey, 1996). Oftentimes, experiences of illness produce “broken narratives” (Kirmayer, 2000), and this is especially the case when one is refused care while seeking emergency health services (addressed in Chapter 5 and 6). Thus, I utilize the mode of interrupted narratives as a means of critical ethnographic writing (Brodkey, 1996). Brodkey claims that “narrative becomes confounded with experience” (p.113) where an ethnographer’s retelling and application of theory is understood as the same kind of knowing as that which one may gather through lived experience. This becomes problematic when ethnographers attempt to take a critical stance towards cultural hegemony because oppression is experienced differently from different positionalities.

In other words, what I understand of colonialism, as a beneficiary of white privilege, is not the same as what colonialism means to an Indigenous person. Critical ethnographic narratives require us to “teach ourselves how to narrate stories of cultural hegemony that make it clear that a negative critique is the process by which each of us confronts our respective inability to comprehend the experiences of others even as we recognize the absolute necessity of continuing the effort to do so” (Brodkey, 1996, p. 113). With humility, I share these stories and my own experiences recognizing that what I can know about relational health care or facing discrimination in an emergency department is limited yet generating deeper understanding of these dynamics through a

decolonizing and collaborative approach is necessary to addressing systemic health inequities.

Chapter 3: Indigenous Health Governance and Relational Care

The head office of the Nuu-chah-nulth Tribal Council occupies the repurposed grounds of the Alberni Indian Residential School, just up the hill from the Somass River and Highway 4, heading out of the city of Port Alberni. Port Alberni is a small city with a significant Indigenous population¹⁸ that developed around the logging and milling industries. Driving up to the NTC office, the edges of the roads are lined with dense blackberry shrubs. One is likely to spot an eagle or raven in this area, and perhaps the occasional bear. The office building is surrounded by a parking lot with a bighouse for ceremony, gymnasium, and a family events building to the right. An expansive and lush community garden spans to the left of the building. The front of the office is donned by a large totem pole and NTC insignia carving. Upon opening the front door, it is not uncommon to hear the secretary teasing and joking with the staff as they enter the building and sign in on the staff board. One can typically find *chumis* (sweets) left on a platter in the waiting area, and often locals come in to sell baked goods, *upsl-kwi* (dried or smoked salmon strips), woven cedar jewelry and other goods produced in the communities.

¹⁸ In the 2016 census, of the 20,325 people living in Port Alberni, 3,710 indicated having Aboriginal identity (Statistics Canada, 2016). This number does not include the population of Indigenous communities living on reserve lands bordering the city limits.

Anyone unfamiliar with the Nuuchahnulth communities may not even be aware of the existence of this central building where key decisions have been made, as they cross the “orange bridge” on their travels to the Pacific Rim. Yet for locals, this building is simultaneously central, mundane, contested, and sometimes even avoided due to its significance as a site of governance, its existence as a workplace, and its troubled history. Over my time spent at the NTC Head Office, I was made aware of ongoing conversations about how to cleanse the area and how to release the trapped souls of children who were lost at the residential school; how to heal from the trauma of that legacy. However, speaking from my own impression, I felt a considerable vibrancy to the place. I believe this was created by all those who arrived to work at this building each morning, greeting one another with smiles and quite often a few jokes. Afterwards, they set themselves down (or stood at standing desks) to undertake the impossible task of providing social, educational, and health services in the context of a dearth of funding, in an effort to undo the systemic marginalization Indigenous communities have faced since contact.

Throughout this dissertation, I explore multiple modes of care, including informal care in communities, care experienced through encounters with the health care system as recounted by patients, and care as provided through the NTC Nursing Services. I begin this exploration by starting at what served as the centre of my field sites, the Nuuchahnulth Tribal Council Health Department, and the efforts of this organization to provide culturally safe health services to Nuuchahnulth-aht. Here I explore cultural safety as realized through a relational mode of care developed within the NTC Nursing Services. Investigating the links between individual care experiences, a health system forged through settler colonialism struggling to embrace cultural safety, and a tribal council that

is actively responding to health impacts of this history requires tracking back and forth between levels of decision-making and acting. As such, in this chapter I move between the specificities of Nuu-chah-nulth governance structures as they have endured and continue to exert influence over life in communities across western Vancouver Island, and the generalities of concepts as they are taken up within Canadian state apparatuses as presumably separate, overarching institutions, as well as the sites where these multiple orders of governance intersect in terms of how healthcare is made available within communities. My focus in this chapter is on the *Hupiimin Wiikšahiiy'ap* (helping us to be well) NTC Nursing Services as a site where circulating ideas such as cultural safety have been translated into specific modes of care which attend to local expectations, needs, and visions for care.

Cultural safety offers a broad concept to talk about the manifestations of power in health care provision. In the context of Nuu-chah-nulth communities, the NTC has developed a unique nursing practice I describe as *relational care* as a way of implementing the vision of cultural safety while drawing from a Nuu-chah-nulth worldview¹⁹. Indigenous governance and self-determination enabled the development of the NTC nursing framework which provides biomedical health services in what is often described as “the Nuu-chah-nulth way,” by drawing on translatable concepts and shaping them into specific modes of care and care practices that are informed by local beliefs, care expectations, and values. Cultural safety intersects with notions of self-determination

¹⁹ NTC nurses also contrasted the NTC nursing approach with “mainstream” nursing by using terms such as relational or culturally safe practice.

because of the focus on rectifying power imbalances and shifting power to patients and communities. Individual autonomy can be understood as linked to the self-determination of nations, in the sense that control over one's own health is tied to community-based control of services.

Investigating the intersection between multiple modes of care invokes the question of how care practices might work to perpetuate or confront health inequity. In addressing this, I argue that Indigenous self-determination over health care delivery reduces health inequities through both increasing access and providing culturally safe care. Furthermore, Indigenous self-determination enables the production of new modes of care. These relational modes of care increase access to health services, provide a site for individuals to overcome past trauma, provide a platform for nation-rebuilding and collective healing, and contribute to the transformation of biomedical standards more broadly. I describe relational care within the context of the NTC Nursing Services by addressing how the ideal of culturally safe care has been translated into practice through Indigenous-led health services. I explore how an alternative vision for care was defined and enacted by community, nurses, and Nuu-chah-nulth leadership. I demonstrate a relational approach to healthcare as healing for both clients²⁰ and care providers and

²⁰ I use the term “client” to reflect the language used by NTC Nurses. In doing so, I recognize the problematic connotations associated with this term as reflecting a corporate model (Downe, 2021) linked to neoliberal ideologies of individual choice (Mol, 2008). However, as I describe in this chapter, the NTC Nursing Services operates through a unique framework rooted in Indigenous values, despite retaining the use of the term “client” as a standard descriptor for the individuals in receipt of nursing care. For this reason, I similarly use the term clients to refer to community members who are regularly receiving care from the NTC Nursing program. In other areas, I use the term “patient” to refer to an individual seeking or receiving care from a biomedical institution such as a hospital or clinic. I also recognize that critiques have been levelled both within and outside of health services research at the use of the term “patient” as overly passive or even dehumanizing. My intention in using this term is not to define an individual as a subject of the health care system deterministically, but rather to mark a moment where an individual's relation or

discuss how NTC Nursing has collectively redefined criteria around ‘care’ through an emphasis on building relationships.

The relational modes of care I will describe are rooted in Indigenous approaches to healing that have existed before, outside of, and alongside colonialism as well as in response to it. As such, relational care cannot be reduced to a response to colonialism, because within these modes of care are currents of ways of being that have persisted since before and despite colonialism, which also provide a powerful response to healing from trauma. Despite the historical and ontological dissonance between biomedicine and Indigenous modes of healing, I bring into question the idea that biomedicine is incapable of recognizing and adopting relational – or more broadly – Indigenous approaches to care. Instead, I am interested in the co-existence and imbrication of social exclusion and relational care, as well as biomedical and Indigenous approaches to healing. I examine the areas of tension between biomedical practices and Indigenous modes of care, as it is within these disjunctures that we may find insights towards addressing health inequities effectively at the local level through addressing specific practices and functions within health care systems.

Situating Indigenous Health Governance

In Canada, public health service delivery is coordinated by the provincial and territorial governments, resulting in distinct health systems in each of the provinces and territories. However, the federal government has assumed responsibility for managing First Nations

positionality is largely shaped by an illness experience and how that experience orients them towards health care providers and institutions.

and Inuit health care, through the First Nations and Inuit Health Branch of Health Canada. Throughout the history of Aboriginal health services in Canada, there have been jurisdictional disputes between the provinces and the federal government over responsibilities for funding and service delivery to Indigenous communities and patients (Waldram et al., 2006). In British Columbia, health care is managed through the Ministry of Health (MoH) and provided through five regional health authorities. Recent First Nations health policy in British Columbia is for the most part premised upon a notion that radical transformations in health care delivery are required to improve the health status of First Nations communities. In policy terms, this is predicated on the practice of granting greater autonomy to First Nations communities over health care administration (First Nations Health Council, 2011, 2012). In British Columbia, The Transformative Change Accord (2005) and subsequent agreements²¹ paved the way for the recognition of Indigenous modes of healing and community control over services as key to improving access to and quality of health services within Indigenous communities (First Nations Health Authority, 2014). An important subset of this accord includes policy directly targeting First Nations health care, which has led to the creation of the First Nations Health Authority (FNHA) in 2013. The FNHA has assumed jurisdiction over the planning, managing, delivery and funding of various health services from the federal First Nations and Inuit Health Branch – Pacific Region (FNIHB) (First Nations Health Authority, 2017).

²¹ The Transformative Change Accord: First Nations Health Plan: Supporting the Health and Wellness of First Nations in British Columbia, 2007; Tripartite First Nations Health Plan, 2007; British Columbia Tripartite First Nations Health: Basis for a framework agreement on Health Governance, 2010; Health Partnership Accord, 2012.

These recent trends in British Columbia reflect late liberalism in the Canadian context, which is marked by increasing devolution of federal responsibilities onto local governments (Million, 2013; Povinelli, 2011). Beginning with the Federal Health Transfer program, approved in 1988 (Lavoie et al., 2015), administrative control over health services has been conferred to registered Aboriginal communities or tribal council applicants. This increase in self-determination has enabled many communities to integrate Indigenous community-based approaches to healing across the nation (Warry, 1998). The NTC was one of the first Indigenous organizations in Canada to participate in the Federal Health Transfer program, as early as April 1, 1990, and has passed two subsequent transfers since. Studies have shown that the Federal Transfer program has improved the cultural sensitivity of care (Health Canada, 2005; Kelm, 1998; R. Smith & Lavoie, 2008; Warry, 1998). Furthermore, Nuuchahnulth communities “report that assuming jurisdiction over medical services has served a decolonizing agenda, defined as increasing community self-esteem, enhancing skills and allowing for a revitalization of aboriginal healing” (Kelm, 2004). However, evidence is currently inconclusive as to the impact health transfer has had on health indices (Wilmot, 2018).

Though promoted as a way to increase self-determination, Indigenous groups have criticized the Federal Health Transfer Policy as an offloading of administrative responsibility from the federal government to Indigenous communities (Kelly, 2011; Waldram et al., 2006), a critique I explore further in Chapter 7. Despite developments such as the Federal Health Transfer program and the creation of the FNHA, Aboriginal health care in British Columbia (and Canada more generally) continues to be characterized by a jurisdictional divide between the services that are provided by the

federal or provincial governments which can lead to gaps in services²² (Lavoie et al., 2015; Waldram et al., 2006). This, combined with the haphazard way greater self-determination over health care administration is conferred and the ad hoc implementation of health services for Indigenous communities – as obligations outlined in treaties and the Indian Act continue to be a source of contention – leads to an uneven development of health services that creates pockets of inequality.

While the federal government has defined “self-determination” through the granting of self-governance, a distinctly Nuuchahnulth governance order has persisted through the *ha’wiih* (hereditary chiefs) and management of *ha’hoolthi* (traditional territories). This Indigenous governance order continues to inform the NTC, which pursues self-determination through facilitating community control over social and economic services and through political advocacy and advancing Nuuchahnulth language, beliefs, and way of life.

The *ha’wiih* (hereditary chiefs, plural) and the associated order of governance continue to have a profound influence on life in Nuuchahnulth communities. The position of *ha’wiih* (hereditary chief) is typically passed on to the eldest male in the family. As explained by Hereditary Chief Maquinna George, the position “signifies ownership of resources, beaches, fishing grounds, forest land, and salmon streams in our home territory. Everything that is valued belongs to the Ha’wiih” (Maquinna George,

²² For instance, Jordan’s Principle, passed through the House of Commons in 2007, addresses jurisdictional payment disputes which have led to life-threatening delays in medical treatment for Indigenous children. This principle requires the service provider of first contact to provide services without delay, and, while unfortunately not fully implemented, it points to the poignancy of this issue in Aboriginal health policy (Blackstock, 2016).

2003, p. 12). Richard Umeeek Atleo, a Nuu-chah-nulth scholar, describes the role of Nuu-chah-nulth governance during his upbringing during the 1940s and 50s. At this time, band councils worked closely with *ha'wiih*. Consensus and mutual respect allowed individual expression within collective decision making. Feasts were often held for occasions and demonstrated a chief's ability to provide. The purpose of gifting in feasts was to give thanks and to recognize interconnection between peoples, the land, and living creatures. A chief's ability to provide was seen as evidence of spiritual power or blessing. Atleo states, "These ceremonies are strongly focused on the importance of relationships, of maintaining protocol, of showing respect, and of demonstrating these attributes through the generosity of food, gifts, and relational oratory" (Atleo, 2004, p. 112).

These governance structures continue to inform the provision of social and health services in Nuu-chah-nulth communities. Health Directors, Community Health Representatives (CHRs), and Medical Travel Clerks play key roles not just as leaders and public servants, but also as a source of support and compassion as "front-line" workers, sometimes as cultural knowledge holders, and as advocates with the ability to lobby on behalf of community members in various political arenas including NTC governance, FNHA, and other provincial and national organizations. Generally, health directors are employees of the First Nation (whether organized as a band or through legislation under the Manuulth Treaty). The balance between governance by an elected council and by the *Ha'wiih* (hereditary chieftainship) holds slightly different forms in each First Nation. However, often these roles overlap or roles in council and administration may be largely occupied by members of a high-ranking family. Historian Mary-Ellen Kelm reflects on a similar situation in her work with the Nisga'a, and suggests that Community Health

Representatives and other community-based health workers provide the most consistent care in communities where “people seldom developed long-term patient relationships” (Kelm, 2004, p. 342) due to locum doctors and high turnover rates. She also asserts that involvement in medical care “works in tandem with their status within the traditional social structure” (Kelm, 2004, p. 344).

My impression is that leadership and mentorship in Nuu-chah-nulth communities is diffuse and not limited to holding a particular office. I was acquainted with individuals who retired from important leadership positions for the NTC or one of the First Nations yet continued to hold influence throughout the communities as an Elder or knowledgeable community member, often called upon to lead important events and to share guidance and wisdom in key areas of debate. As active members of their respective communities, and often also being descendants of *ha'wiih*, these individuals continue to contribute to life in communities through these multiple channels of influence both formally (such as through organized meetings or legal hearings) and informally through social ties.

Cultural Safety in Policy and Practice

In addressing the various interpretations of self-determination as they relate to biomedical and relational modes of care, cultural safety offers a kind of boundary-crossing concept. This is because the concept of cultural safety has enabled dialogue between the health needs expressed by Indigenous communities in British Columbia, health service delivery, and policy frameworks. The concept of cultural safety was originally developed by Irhapeti Ramsden, a Maori nurse. The concept was devised to improve upon the cultural competence model which was failing to adequately address the needs of culturally

diverse patients in New Zealand (Brascoupe & Waters, 2009; Kleinman & Benson, 2006). The concept of cultural safety has gained currency across nursing literature and health policy in Canada (ANAC, 2009). Cultural safety is integral to the framework which guides the Nuu-chah-nulth Tribal Council Nursing Services. It addresses the question of how cultural difference can be attended to within the clinic through a critical assessment of power relations between patients and healers. This theory shifts clinical understandings of culture from belief systems to relations of power in which dominant groups have dictated social structures such as health care (J. Anderson et al., 2003). In a Canadian context, Brascoupe & Waters (2009) define cultural safety as “an approach to healthcare that recognizes the contemporary conditions of Aboriginal people which result from their post-contact history” (Brascoupe and Waters 2009, 6) including historical trauma and loss of cultural cohesion. Smith et. al (2006) describe culturally unsafe care as a result of systemic ‘othering’ and marginalization of Indigenous people. In this context, “imposed models of healthcare intervention based on racialized explanations and prescriptive solutions for health concerns experienced by Aboriginal people create an unethical paradox of care” (D. Smith et al., 2006, p. 29).

In looking at how culturally safe care is described in health policy, ‘culture’ is often described through a constructivist stance, to update static and essentialist notions of culture often circulating in clinical domains. Through the lens of cultural safety, ‘culture’ is intended to be viewed as “being enacted relationally through history, experience, gender and social position” as well as a “sociopolitical construct with underlying power relations” (ANAC, 2009, p. 1). Cultural safety, as it is currently employed within nursing education, Canadian health policy, and by the FNHA, is distinguished from previous

notions of cultural sensitivity (awareness and respect for difference), and cultural competency (First Nations Health Authority, 2015). In the FNHA definition of cultural safety, cross-cultural understanding is an ongoing learning process because culture is embodied in different ways in different individuals, often intersecting with other forms of identity. This reflects the argument posed by medical anthropologists that cultural competence approaches sometimes reduce social complexity to a technical skill which can be mastered by learning a set of fixed core beliefs seen as associated with a particular cultural identity. According to critics, this approach to cultural competence is particularly problematic as it can take attention away from uncovering what is truly at stake for patients regarding their health concerns as situated within their individual lived contexts (Kleinman & Benson, 2006; Taylor, 2003).

In the culturally safe model, nursing education is foundational and nurses are encouraged to reflect on their own values and assumptions brought to the clinical interaction (J. Anderson et al., 2003). Cultural safety also emphasizes the links between health and socioeconomic status. Therefore, cultural safety considers how a group is positioned within society, rather than ‘cataloguing’ beliefs and custom such as occurred with early versions of a cultural competence model (J. Anderson et al., 2003; Jenks, 2011; Kleinman & Benson, 2006; Taylor, 2003). By focusing on the power imbalances within health encounters, cultural safety emphasizes “transforming attitudes, policies, and practices in health care” through greater understanding and responsiveness to the colonial experience (Browne & Fiske, 2001, p. 127). As a leading advocate in the shift towards culturally safe health care, the FNHA definition is worth citing:

Cultural safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care (First Nations Health Authority, 2015, p. 10).

Beyond a focused application to Indigenous health, cultural safety is more broadly “relevant to the clinical context and [health care] employers should be encouraged to consider how ‘cultural safety’ can be enacted in the workplace setting” (ANAC, 2009, p. 4). However, there remains a “know-do-gap”²³ in terms of how to adapt the principles of cultural safety into clinical practice. For instance, there seemed to be a disjuncture between the ideals of cultural safety and ongoing experiences shared by community members, who emphasized ongoing dehumanizing and dismissive experiences in the health care system.

In the context of my research, the concept of cultural safety offered a linguistic tool to invite conversations about how community members and health care providers envisioned how health care encounters could and should be. In using the concept of cultural safety, ideas are often evoked around historical trauma, colonial oppression, and Indigenous resurgence. Thus, the conversation expands beyond discussing cultural meanings attached to care, to the affective values embedded in acts of care (whether abandonment, dismissal, or alternatively, *isaak* - respect). As such, cultural safety transverses the boundary zone of health care (Mattingly, 2006), providing an opportunity to “transform the terms of discussion of First Nations health matters” (Wilmot, 2018, p. 5). Despite being an imported concept, cultural safety also transcends multiple levels,

²³ A “know-do-gap” is a term commonly used in health policy research to identify divergence between evidence-based practices and what is actually done in clinical spaces.

from individual autonomy in health care encounters, to the social determinants which influence the health care experiences of Indigenous peoples, connecting the interpersonal with the systemic.

Framing my work and conversations around the concept of cultural safety did not come without challenges. While the concept has currency across my field sites, there were instances where I was asked to define its meaning, at times in front of large groups of people. This caused two issues for me. The first was that my intention was for participants to define their most pressing concerns about health care access, and to direct me to what was most important in terms of their own health care experiences. Such an approach can be challenging to follow when a conversation is opened by defining a highly value-laden concept²⁴. The second problem was that defining cultural safety requires discussing societal power imbalances, in which case I am identified with the *mamat'n'i*, the colonizers, the ones who already have the power. Thus, I spoke with deep concern that my description of cultural safety came with an implicit (and seemingly condescending) assumption that I am addressing victims of structural violence. However, while at times some participants may have described their experiences as being victims of discrimination or institutional neglect (while others had not), *victimhood* would not be an appropriate identification for any of the individuals with whom I spoke. Nor does it define how I thought of this project while in the field. Despite the immense difficulties in

²⁴ At times I feared the terms of our conversation had already been given shape by my defining a term we would use to translate our own experiences and understandings to one another during the interview. In these moments, I relied on my conversations with nurses, evoking the language they used to describe the concept, such as “providing care on the patient’s own terms,” “care that is respectful of patients’ needs and wishes.”

speaking about cultural safety, I continued to do so as a common language to communicate the topic at hand without pinning it down to one singular understanding. And despite my concerns, participants found ways to take from my descriptions opportunities for them to introduce and speak about their own most pressing issues. Thus, cultural safety provided a framework for talking about how alternative and more equitable visions for care can be mobilized. As such, it identifies the link between clinical encounters and Indigenous self-determination over health governance in the effort to address the health inequities faced by Indigenous peoples in western Canada.

Enacting Culturally Safe Care

The NTC Nursing framework can be understood as a local enactment of the vision for cultural safety. As informed by the concept of cultural safety, the NTC nursing services engage in a critical examination of culture, power, and colonialism. The NTC nursing services describe culturally safe care as the responsibility of nurses to “examine their power in nursing relationships and ensure care is delivered in a way where clients maintain self-determination and their health needs in their daily lives are met” (Nuu-chah-nulth Nursing Services, 2013). As such, the focus is on conferring power and decision-making within the care encounter to clients and their families.

The NTC nursing framework was originally developed in the late 1990s and draws on Nuu-chah-nulth culture and wisdom to foster *ha-akimis* (a strengths-based approach) through building on clients’ cultural ways of knowing alongside biomedical care. Developing the framework and receiving approval from the College of Registered Nurses in British Columbia involved several years of consulting with Elders and community health representatives, codifying the collective vision in a graphic

representation, and working with external consultants to find nursing theories that complemented the vision and could be drawn upon for legitimacy.

When discussing the NTC Nursing Framework with me, nurses used the terms “relational” and “reflexive practice”, to indicate an emphasis on relationship building as an integral part of what they do as nurses. The NTC Nursing Framework was also described as client-led, community-driven, and culturally relevant. While these terms hold unique connotations in nursing theory, these diverse approaches were deliberately brought together through the creation of the NTC Nursing framework. Apparently, it had been challenging to incorporate Nuu-chah-nulth values into a framework that was still legible and legitimate according to dominant nursing standards. In practice, however, the nurses do not experience these different influences as contradictory, rather they make them work together through the specific care practices I describe in the following sections.

Relational and Reflexive Practice

Relational practice is both a nursing theory infused within the NTC nursing framework as well as a dimension of care and caregiving responsibilities inherent to Nuu-chah-nulth ways of relating and belonging. In nursing theory, relational practice is defined as a remedy to “liberal political ideology” (Zou, 2016), which has influenced nursing through an emphasis on nurse-patient relationships as individualistic and paternal in nature. When translated into practice-based applications such as nursing, relationality emphasizes the role of social context and responsibility in patient and healer encounters and requires nurses to afford time to understand how contextual factors influence their patients’ health (in terms of age, ability, gender, economic or cultural factors and so on). Relational

practice holds a prominent position in theories of nursing practice, as a means of understanding responsibility to patients as embedded in the patient's social context, both in terms of attending to their immediate needs and advocating on their behalf (Woods, 2012).

In a broad sense, the term relational was used in conversation with NTC nurses as an antithesis; a relational way to care could be understood in opposition to “mainstream” nursing, or biomedical, institutional approaches to care. However, the nurses were also quite specific in how a philosophy of care as relational infused their practice. ʔaʔiñu, a Community Health Nurse who identified as “settler,” explained that:

Because the relationships are put first, there's just this basic less utilitarian stance toward what one is doing because of the relationships. So, my nursing practice as a community health nurse with the NTC can look like hanging out and chatting with the people when they're around. I'm not talking about their health. I'm not asking any questions, something about it might come up. I'm not directing the conversation.... And I actually consider that to be part of my nursing practice. It's connecting, it's cultivating relationships, it's being available to people (interview, March 28, 2018).

Relational practice ensures that the relationship between the care provider and client takes primacy in every health care encounter. However, this does not negate or underplay the role of the nurse as a medical professional. Relational practice was described as necessary to serving Nuu-chah-nulth communities, because, as one nurse described, “if you don't build the relationship, often you can't get to the task at all” (NTC Community Health Nurse, interview, March 27, 2018).

Though the NTC Nurses generally expressed an appreciation for the relational approach, several nurses expressed that building relationships with clients and community took a considerable amount of time, and in some cases, additional learning

for the nurses themselves. ʔišmapt, a non-Indigenous Community Health Nurse, shared her experience adapting to the NTC Nursing Framework:

There was [a learning curve]. I was again very again task orientated, “I gotta do this blood pressure, I gotta do this, I gotta do that.” It was like I get to sit here and have tea. It was kind of hard to, I guess to chill, relax and take a breath. And just be present. Not have to think about the next thing I have to do. It’s learning to work in silence. That it’s okay to take that time to remember or think or process (interview, December 14, 2018).

In relational practice, interpersonal values such as *Isaak* (respect), *aphey* (kindness), and *hupee-ee-aulth* (helpfulness) extends from the interpersonal to community and place.

Ticma, a non-Indigenous Nurse with strong familial connections to Nuuchah-nulth communities, explained:

That was one of the reasons why I ended up coming working for the NTC, was because, from what I understood, as a nurse you’re given the time and the opportunity to really develop rich relationships with your clients. And it’s not just relationships with your clients, relationships with their family, it’s relationship with their community, relationship with the land, and nature, and the ocean (NTC Home Care Nurse, interview, February 28, 2018).

Relational practice for NTC nurses also extends over time and across generations.

According to ʔišmapt:

It’s being a part of our clients’ journeys. They are allowing us to walk with them and just be a part of that. It’s a real honor to watch these babies, some of them being born, to watch them grow up. I’ve watched these children grow up and then some of them are having children. You become a part of the community, whenever they see you. I’m Aunty to a lot of children now (interview, December 14, 2017)

Relational practice also creates space for cultural resurgence to take place. Kuunaa, an Indigenous nurse, explained how home visits were a meaningful experience for her as well as her clients, as it was an opportunity for elders to impart history and wisdom:

If there is no real urgent client care needs, then you find work to do. So sometimes, if it’s a quiet day, I will go visit, like go do a “general visit” we call it. For elders, or people who we’ve seen but don’t need regular visits. It’s more like a social visit.

Cause it's a like a learning opportunity too. For nursing, for me ... Family histories or some Elders will share like myths and legends, or they'll share political histories or stories about old wars. Territories. They are so full of knowledge and they love to share. So it's like a nurse check in, but I find elders love to share what they know, that's their role in communities. They often say they feel like people don't visit them enough. And they have all this knowledge, but not many people come. But they said thank you to me for listening. So it's good for both of us I think (interview, December 11, 2017).

Relational care, as part of an implicated way of being, is also a reciprocal mode of care. Many NTC nurses would agree that the attention and effort they invest into their role as nurses is reciprocated through the sharing of wisdom and community knowledge, and through small or large acts of acknowledgement made by community members. Through the enactment of relational care, nurses are folded into community life by learning about the lives and histories of those they care for. In this way, the nurses also participate in the recollection and circulation of cultural knowledge.

Reflexive practice was another common term NTC nurses used to describe their nursing approach. Reflexivity was described as reflecting on one's own thoughts, feelings, and assumptions either individually or with colleagues. Importantly, reflexive practice supported a culturally safe approach to care by requiring nurses to address how discrimination can factor into health care experiences, and their own role in mitigating this. *ʻālaʻālu* reflected on how reflexivity paired with relational practice can mitigate bias from interfering in the health care encounter:

Cultural safety means one has to be aware of one's own tendency towards stereotyping that is going to happen. So there is self-awareness that just needs to happen around that. Which in my experience is assuaged, or relieved if you will, through building relationships. Not to say there is a colour-blindness that happens, but then there is something else that takes over the relationship and that's just human to human friendliness, professional friendliness (interview, March 28, 2018).

Reflexivity was described as an activity necessary for dismantling colonial power relationships embedded in health system structures and standards, and to challenge any internalized stereotypes. λaλiñu further commented that she understands cultural safety as “knowing the historical and ongoing reality of settler colonialism. And from the experiences and voices of Indigenous peoples” (interview, March 28, 2018). Reflexive practice was identified as fostering a supportive team environment and collaborative problem solving by affording time to come together to reflect on difficult client cases, key to reducing burnout in a demanding workplace.

Client-Led and Community-Driven Care

Client-led care was described by Hupimin, an Indigenous nurse, as a commitment to “go in and provide the best care that they are open to receiving” (interview, March 1, 2018). Inviting or offering care relationally implies initiating a relationship with clients who ultimately determine the care they wish to seek, whether family immunizations, information, regular blood pressure monitoring, or a “general visit.” In nursing theory, a client-led approach emphasizes viewing “patients as whole persons” rather than a diagnosis (Registered Nurses Association of Ontario, 2002). Other key features of a client-led approach, according to nursing theory, include “advocacy, empowerment, and respecting the client’s autonomy, voice, self-determination, and participation in decision-making” (ibid.)²⁵.

²⁵ In other words, client-led care can be understood as a care approach in which the client’s goals coordinate care and lead decision-making. This emphasis is comparable to other approaches in health care such as person-centered and family centered care. The focus in person-centered care is similarly on a patient’s involvement in medical treatment and is often associated with debates around access to medical information. A family-centered approach, rooted in pediatric medicine, recognizes that patients are

Client-led care was described as specific to the NTC Nursing Services and in many cases necessary to connecting with clients who have had previous negative interactions with the health care system. Client-led care was also described as an integral component of culturally safe nursing: “people have to feel *safe*. People have to feel secure, honored, equal to, not being judged. If they require it, they require it. I’m not to be the one to decide” (interview, December 14, 2018). Āusmit, an NTC Home Care Nurse provided an example of how a client-led approach applies to her own practice:

You know we might go in with an agenda and say “well, they have high blood pressure, and they’ve got diabetes and so we’re gonna talk to them about their blood pressure and their blood sugars and talk about nutrition.” But we can go in there, and they don’t want to talk about any of that. So it’s not for us to, we just don’t put that on them. If there is something else going on, that they want to talk about. You know, you have to get back and address those things, but it has to be done in a non-invasive way ... Or you might not even talk about it at all. There might just be something more pressing ... So we will come back to it. There’s nothing urgent about it. They determine what’s important (interview, February 8, 2018).

In the context of NTC Nursing, while the nurses may present an agenda while visiting, for example providing strategies and techniques of chronic disease management, the agenda is never imposed.

The client-led approach is not only integrated into how NTC Nurses work with clients, but also within the structure of the NTC Nursing Services and programs offered, as well as the use of collaborative and detailed charting processes. In developing the programs offered by the NTC Nursing Services, the client-led approach extends from the individual level to community, by integrating a nation-driven approach to programming.

connected to families, that social context and obligations influence health, and that families carry the weight of caregiving responsibilities. In this case, I use the term “client-centered” to illustrate how NTC Nursing Services have moulded a dominant nursing framework to fit with community care expectations.

For instance, NTC Nurses work collaboratively with leadership within each of the Nuuchah-nulth Nations to facilitate health education, workshops and events that reflect the values and needs emphasized within the communities.

Several NTC Nurse participants reflected that at times, a client-led approach can be challenging to balance with encouraging clients to be more engaged in their own health care or meeting required tasks such as immunization. The way NTC nurses balance being effective healthcare providers with letting clients direct their own care outcomes was also described as acknowledging each client case individually and relying on having strong relationships with clients and their families to know when it's appropriate to give reminders, invite themselves in, or go ahead with a course of action and when it is more appropriate to hold back and check back in at another time. This requires a level of intuition that recognizes that information about the clients' needs and preferences does not just come from what they tell care providers directly, but also in how they relate to them.

Culturally Relevant and Responsive Care Delivery

NTC nurse and community participants described the NTC nursing approach as rooted in Nuuchah-nulth values and spirituality. Ongoing consultation with Elders has been key to the development of the NTC nursing approach. Many believe that the NTC nursing approach provides an avenue for the resurgence of culture by offering a way for families who may feel disconnected to reconnect with the traditions of their family or community. Kakawin, a Nuuchah-nulth Elder, shared an example of how a cultural practice was given new life through the Community Health Nursing program:

Nanayuksa, the baby welcoming, came from an Elder. I had never heard of it! So the nurse started exploring and asked Elders. They said that nobody does it anymore but it used to be a practice. They would go to the house, sing songs, and give gifts to the singers. So everything was tying in together and became part of the nursing program. The first we had was at the friendship centre and only two moms came. The nurse that held it was sad. But I said, “one would have been a success and now you have two here!” So the nurses always really worked with the Elders (interview, August 28, 2018).

The *Nanayuksa* (baby welcoming) demonstrates how self-determination over health care provided an avenue for cultural resurgence, as an almost forgotten tradition was given new life through maternal and child nursing.

Examples were shared that demonstrate how Nuu-chah-nulth culture and traditions have been incorporated into the NTC Nursing Framework or supported and encouraged by nurses. As was emphasized by Ticcma, a nurse serving the central region, the NTC nursing approach is to:

Respect cultural practices in any setting; making space and time for it . . . The NTC nursing approach is based in their values, their spirituality. It really helps you understand why people make the decisions they make. And it helps you support them in the best possible way to access health services (interview, February 28, 2018).

As was explained by nurses, becoming immersed in Nuu-chah-nulth culture, such as attending potlatches and family gatherings, is an inherent aspect to a relational approach and building meaningful connections with the communities. Along with participating in cultural events, NTC nurses incorporate Indigenous culture into their practice by discussing with clients their cultural values and beliefs and supporting the use of traditional medicines when discussed or requested by clients. Qawii, a young mother from Ahousaht, described the support she received from NTC Community Health nurses throughout a difficult birth, and how their support of cultural practices pertaining to

pregnancy and early motherhood helped to foster a meaningful and supportive experience:

When I was pregnant, they [NTC Community Health Nurses] ask - because there is a belief in our tradition, we take the placenta after birth and put a whole bunch of things in there that you want the child to aspire to be, and you bury it. And they were all into it and then they were all giving suggestions of what to put in there. I actually, I couldn't do that because I hemorrhaged and I lost 90% of my blood supply, I died twice on the operating table. And they transfused blood in. And he was born exactly at four o'clock. I held him, I blacked out and woke up at ten o'clock at night. So, I was like "ok what happened?" But they were all helpful, and once I got back, they were like "you're not allowed to do that anymore!" Because my mom is close friends with them that they are all pretty close and once they heard what happened, they are like "you are not allowed to do that anymore."

. . . But he is becoming his own person. Yeah, and with the first birthday [the same NTC nurse] was around. And then, somebody's tradition, we are supposed to cut his hair. So, we did that, and my grandpa, she was like "well what did your grandpa say?" I was like "he said we have to shave him." And she was like "no, I don't want you to! But you have to!" And she was just all for it. And she was like "ok then we'll just shave his head" (interview, May 2, 2018).

As described by the Qawii, NTC nurses continued to be a source of support throughout her pregnancy, birth and over the first year of her son's life. The birth did not pan out as was hoped for, however, by holding concern for Qawii's birth wishes – including the importance of observing cultural practices – and maintaining a connection over the years, the NTC nurses become a source of support in finding strength and meaning within a difficult birthing experience. Many interviewees noted that beliefs and cultural practices vary greatly among individuals and families, and that this diversity must be acknowledged within culturally safe health care delivery.

Enacting Relational Practice

The NTC nurses described specific actions they incorporate into their practice which ensure consistent culturally safe and respectful care delivery, including taking time, fostering trust, building connections with communities, and advocating on behalf of

clients. “Taking time” was described mainly by nurses as something that set apart the NTC approach from mainstream nursing. The NTC nursing approach involves being present, prepared to address whatever situation may present itself, and spending as much time as necessary for meaningful client visits. Taking time with clients was described as instrumental to relational practice, because it creates space to address concerns, hopes or wishes that lie outside of specific nursing tasks. Hupimin, an Indigenous nurse, explained:

Sometimes they need us longer in the homes. Or maybe not quite as long, so it just varies, and we are able to adjust our visit accordingly. Just sometimes they may need more than taking care of their blood pressure or blood sugars. Being a listening ear to them (interview, March 1, 2018).

The NTC Nursing Services are distinct from other nursing providers as there is no imposed time limit for patient appointments. Whereas the regional health authority books appointments in fifteen-minute blocks, management at the NTC expect that nurses may see significantly fewer clients per day, but that each client visit is meaningful.

Taking time and being available were also described as key to reducing barriers and making care more accessible for clients who may have had previous negative encounters with health care. C`a?ak explained:

And then the other piece is really trying to be present when something presents itself because there are so many barriers to access. So try not to, like I still kind of get in trouble because I walk too fast. Like slow down. And if you slow down, you’re available. If you walk too fast, you’re on a mission (NTC Home Care Nurse, interview, March 1, 2018).

She further explained that taking time with clients was necessary to foster trust and to create a comfortable environment to discuss sensitive health concerns:

It's often at the end of the hour that what they are really concerned about gets expressed. So when you have that sense of I should stay, you allow that time.

Whereas it's actually real easy to go check "good, good, good" and then off to the next house. So we resist that temptation (interview, March 1, 2018).

NTC Nurses further explained that taking time was necessary not to just ensure clients' concerns are addressed, but also because challenges a relative may be facing could be brought forward as well, once a trusting space has been established. In this sense, taking time is a necessary step to reducing barriers to care and making care available for families who may otherwise avoid health services.

In reducing barriers to care, fostering trust between clients and care providers is a necessary objective, which is supported through taking time. Nurses must contend with the history of colonialism and the role nurses have historically taken as figures of oppression. C'aʔak explained that:

There is also a bit of a power dynamic that in the past, nurses have been part of taking children away and making decisions outside of family decision. So I find there is, like we have to be *safe* to people. So I think that older people that are having trouble functioning at home aren't necessarily going to tell us because they don't want to leave home. So we have to read between the lines and figure out ways to help them be really safe at home. And find some sideways for us to promote that kind of safety in their home when they are not going to tell us that they are struggling (interview, March 1, 2018).

Kakawin, a respected Nuu-chah-nulth Elder and retired nurse, explained that building trust with clients allowed health care providers to work effectively through challenging situations. In describing the impact of building trust with clients, she shared a powerful example:

We always told our nurses to report if they saw something wrong, especially with children. The nurses didn't want to, they didn't want to be spies. One nurse saw something that really bothered her. She felt she had to do something. We advised her to tell the mom that it's in the contract that she has to report it. So she told the mom upfront and also said she wanted to keep working with her [as her nurse]. It ended up being okay because she was upfront with that client (interview, August 28, 2018).

Trust, openness, and professional accountability can be effective tools to maintaining productive relationships with clients who may be going through challenging experiences. In the above case, the nurse's obligation to report potentially dangerous situations harkens back to the history of interference from nurses and social workers in the apprehension of children. However, in this case the nurse and client were able to address the concern collaboratively, knowing they would follow legal requirements as needed but that the cohesion of the family and their rapport with their nurse would remain priority.

NTC nurses expressed that completing tasks within their nursing role, such as providing foot care or immunizations, was contingent on first establishing meaningful connections with the communities. Building connections with community is a necessary first step to building trust and rapport with individual clients. Being well connected to the communities is also important in terms of keeping up to date with what is going on in the community and who is present or available. Word of mouth is a key way that care is afforded to those in need. It allows nurses who do not live in the communities to get informed about new clients or changes in existing clients' health. It is also often how nurses get in touch with potential clients, who may not have computers, cellular access, or may be traveling.

Şay'ama Nuči, an NTC Community Health Nurse, described the extended amount of time it took for her to build relationships and adapt to a new way of connecting with families living in northern Nuu-chah-nulth communities:

But after two years they're hollering at me out the window we got fresh bread. And I've never gone to a door and just gone in, I've never done that, I knock at the door, if nobody's there I go away. I had to learn not to do that, I had to learn to poke my head in the door cause they're all upstairs, I have to learn to open the door, that's

again something I never do. I have to open the door, and I have to shout up the stairs and go, "it's the nurse!", and you hear them call them back, "hide the children!" [laughs] But that's after two years that I could do that (interview, March 2, 2018).

The NTC nurses have been encouraged by community members to visit homes directly, and in some cases, to even come in the door and shout to see if anyone is home. NTC nurses regularly check in with the Community Health Representatives living in the communities, as well as other members of the First Nation's administrative staff to catch up on news regarding who has requested a visit from a nurse, who has been admitted to or released from hospital, and other pertinent information. NTC nurses enjoy this aspect of their work environment, where "everyone knows what everyone is up to," as a context through which relational care thrives.

Clients also reflected that the efforts of NTC nurses to build connections and stay in the loop with communities contributed to positive care experiences. A commitment to be present in the communities was often discussed as a sign of respect that reflected Nuuchahnulth values. For example, Kakawin explained:

My sister told me about a nurse up north, who was so dedicated about doing homecare visits. You know Ehattesaht, the houses are along a really steep hill. She saw the nurse going up the hill and it was really icy! She was so determined! (interview, August 28, 2018).

Culturally safe care was defined by community members as having a health care provider who advocates for you or your loved ones and ensures that you are accommodated throughout the care journey. Attending to clients throughout their health care journeys, providing advocacy, and translating medical information was outlined by NTC nurses as key to their role as Nuuchahnulth nurses. Community and client participants discussed the importance of advocating for adequate health services and

challenging ongoing discrimination within the health system. Anecdotes were shared that illustrated the role NTC nurses often take on in advocating for health equity for Nuuchah-nulth communities. Kuunaa, an Indigenous nurse expressed that:

If we [nurses] can be the middleman, between clients who sometimes don't have the voice to speak up to the government or their band offices, we can be a middleman to such services, what we see their needs. That's culturally safe in my eyes (interview, December 11, 2017).

Similarly, many community and client participants discussed the importance of advocating for adequate health services and to challenge ongoing discrimination within the health system.

In advocating for health equity for Nuuchah-nulth communities, NTC nurses regularly translate medical information regarding diagnosis and treatment options, follow-up to ensure supports or appointments are put in place in a timely manner, research funding or supports to keep elders safe at home, support clients to follow through on complaints, and connect families to resources available, such as insurance claims, counselling, social-work, applications for medical devices. Importantly, NTC nurses advocate for increased access and continuity of care and identifying cases of discrimination. Y'am'a, a Home Care Nurse, stated that it was almost weekly that she received complaints from clients that "their doctors, or the hospital emerg., and mistreatment, the way they are spoken to. And we are always encouraging them to write letters, or we can help them get letters written up" (interview, December 7, 2017). The NTC nursing services were acknowledged as a remedy to discrimination and trauma associated with health care through the culturally safe, relational, client-directed, and culturally informed nursing approach. Through the above examples, I hope to have

illustrated a relational approach to care, as demonstrated within NTC nursing as building connections with Nuu-chah-nulth communities, taking time, and fostering trust, and as demonstrated as a Nuu-chah-nulth value by emphasizing connection, family, and understanding.

Conclusion

Though experienced as separate from “mainstream” healthcare, relational modes of care do not exist in isolation from biopolitical structures of care. The relational modes of care I have described are informed by *hahuupa* (teachings) and Nuu-chah-nulth approaches to wellness that have existed prior to and alongside the establishment of biomedical health services. A relational approach to care offers a powerful response to the fraught relationship between First Nations and state institutions such as health care. Thus, it is a mode of care which must be understood within the context that “we [Nuu-chah-nulth-aht] are a grieving nation” (health leader, personal communication, May 2018). Healing in Nuu-chah-nulth communities must contend with the violent legacy of colonialism, as well as the lingering impacts of generations of health disparity linked to historical trauma, economic marginalization, environmental contamination, social determinants of health (including substance use, poverty, and domestic violence) and inadequate access to appropriate health services. Relational care is developed in response to the traumas wrought by colonization, including the role of health care as a colonial institution, however, at the same time it is informed by ways of being that have persisted for millennia. Thus, relational care is simultaneously embedded in biomedicine and western philosophies of care, a response to or remedy for its harmful effects, and an alternative to western forms of medicine.

Anti-Indigenous discrimination continues to persist within health care, including differential care and experiences of inequity in terms of access to health care. Due to this, it is a common occurrence for individuals to refuse care or altogether avoid health clinics. Accessing health services can be retraumatizing for individuals who have attended or faced the intergenerational impacts of residential schools and Indian hospitals. This indicates an overall context of general mistrust towards healthcare within Nuu-chah-nulth communities, which greatly factors into health care encounters and whether patients feel heard, acknowledged, and cared for by health care providers. The NTC nursing services were acknowledged as remedy to many of these issues, through the culturally safe, relational, client-directed and culturally informed nursing approach. The interviews reveal examples of how the NTC Nursing framework and nurses have profoundly contributed to increasing access to health services and supported clients to overcome challenging situations. Ticcma shared a moving story of an experience with a client that illustrates the impact of relational practice in nursing:

For me to be able to provide nursing services to this one gentleman, I had to spend, I would visit him on a weekly basis for a year, and for the first, let's say six months, he didn't say very much to me but he'd let me come and take his blood pressure and check on him. But he wouldn't let me change anything, he wouldn't let me do any more and it was really obvious that he needed more services. Like he needed foot care, he needed medication management and needed bowel protocols in place. So, after a year of visiting him on a weekly basis, he started to open up to me telling me stories about his past and his family, and he let me cut his toe nails²⁶ and it made me cry 'cause I knew it was so much, like it was a big deal for him, to let somebody touch his feet, right? (interview, February 12, 2018).

²⁶ Providing foot care, including nail trimming, for persons with diabetes requires specialized training. Nerve damage and lessened blood flow resulting from diabetes reduces the body's ability to heal. Persons with diabetes are at risk of complications resulting from infection related to foot injuries. As such, foot care is instrumental to maintaining quality of life for persons with advanced diabetes.

As this story demonstrates, the NTC Nursing Services have increased access to care for Nuu-chah-nulth-aht by both fostering trust and creating positive healthcare experiences, as well as increasing the reach of services.

The NTC Nursing program actively challenges existing unmet health needs by empowering families and individuals throughout their health journeys by providing education, advocacy, and “deep care”. Hasp’iqak, a Nuu-chah-nulth health leader, explained:

When I’m here and I see them [NTC nurses] interact with the members it seems so positive. They seem to really take an interest and have a deep care for patients and clients, in their care. Always try to work and see how they can make it better. That’s the kind of things I have noticed . . . I think nurses are an important support that way because they are the ones who see the patients, they are the ones who have built relationships with the patients, they’re the ones who have seen them through the challenges and good times in their lives, when things are going well. I think doctors sometimes really need to turn to them to find out (interview, Thursday March 15, 2018).

Through the relational, client-led, and culturally relevant nursing approach, NTC nurses are able to foster meaningful trust and accountability with clients.

NTC nurses support clients through both health crisis and routine appointments.

Našuk, a Uchucklesaht Elder, reflected on how an NTC nurse supported her in overcoming previous negative experiences in the local hospital to navigate the health system and access the care she sought for:

I really wish – this is a huge wish – that this hospital would treat us like they treat everyone else. Talk to us, tell us what they are doing, what the medications are. Don’t leave us in limbo, that’s what happened at residential school, waiting around to be told what to do.

Sometimes the NTC nurses come into the hospital to be with us. It’s not even part of their job description but they do it any way. Bring information for us. Sometimes nurses will just go for a walk and talk. Even when they are tired, they are there to share information and enjoy the day with you. It is very comforting. It makes you feel supported and safe. I don’t know what I would do without. [My nurse] has

done all kinds of research to help me, given direction of where to find help, talked to pharmacists for me (interview, June 21, 2018)

According to NTC clients, a profound impact of the NTC Nursing approach was to provide information so that clients fully understand their diagnosis and treatment plan and can manage their own health needs.

Nuu-chah-nulth health governance has facilitated the translation of cultural safety into specific modes of care, which I have described as relational. It is the ongoing influence of *ha'wiih* and *hahuupa* through self-determination that has enabled new modes of care. It would be false to claim that NTC nursing practice lines up perfectly with community expectations, or that individuals and communities feel uniformly well-served by the NTC across all regions. However, the relational approach developed by NTC nursing has supported the health and wellness of community members in profound ways through a reflexive, client-led and culturally relevant approach.

In the proceeding chapters, I build on this understanding of a relational mode of care as a response to pervasive health inequities faced in Nuu-chah-nulth communities, both in terms of access to services and racialized discrimination within the health system, by addressing discourses which structure the health system by perpetuating inequity. My aim is to uncover the instabilities as well as the sites where self-determination of health services has shown the possibility for more pluralistic and relational modes of care. By recognizing both sites of oppression and empowerment, we can then see where and how divergent approaches to care are commensurable or not. This further emphasizes the importance of a relational approach, and how this information on forms of oppression and empowerment can translate into how to effectively build equity into the health system. I

am proposing a shift beyond simply recognizing that inequity exists and that something should be done, to investigating the specific spaces where discriminatory discourses garner discursive power, as well as the sites where alternatives have been made possible.

Chapter 4: Health Inequity, Colonialism, and Access to Care

Figure 3: Buildings and shoreline approaching Kyuquot, BC June 19, 2017.

In June 2017 I was invited to travel with a group of NTC nursing staff and affiliated Indigenous researchers to attend a meeting in one of the Nuu-chah-nulth nations, Ka:'yu:'k't'h'/Che:k:tles7et'h'²⁷ (Kyuquot). Leaving from Port Alberni, our group of travelers convened at the rental vehicle outlet and boarded a heavy-duty truck that would serve as our transportation for at least part of the journey. We spent the better part of the

²⁷ Ka:'yu:'k't'h'/Che:k:tles7et'h' First Nations is a signee to the Maa-nulth Treaty and is an amalgamation of the Kyuquot and Checkleset communities.

day traveling north. “Did you bring your passports!?” an Elder and reputable member of a chiefly family from Ahousaht, joked about having temporarily passed across the Nuuchah-nulth border into Kwak’waka’wakw territory as we stopped to fuel the truck.

Further north, we turned off from the paved highway and headed deeper into the stunning landscape of dense rainforest, towering waterfalls, and devastating swaths of clear-cut logging. After several hours of driving on what seemed at the time to be terrifyingly exposed rough logging roads, we rested for the evening in the small and isolated village of Zeballos. After an early morning spent traversing more logging roads and riding a water taxi that crested rolling waves over the open Pacific Ocean, we arrived in the village of Kyuquot.

The meeting was intended to engage members of the communities that comprised the northern region of Nuuchah-nulth territories in a conversation about applied health research priorities. We convened in the newly renovated Kyuquot Health Clinic, which council members lamented was “still” empty and not being used by any medical professionals at that time. What proceeded was a brief, humble presentation of ideas shared by the invited researchers, followed by a lengthy and frank conversation of ongoing unmet health needs within the communities. A common theme addressed that day was the lack of emergency services and how the unpaid volunteer First Responders needed more support in providing emergency care in their communities. Part way through the discussion, the excitement in the room hushed to accommodate the words of a small, soft-spoken Elder, ʔiihmisuk, who had been patiently seated next to me. I glanced at the still, intently focused faces around the room as ʔiihmisuk shared what was for me an utterly heart-wrenching story. She shared about her present health challenges

and how she had recently had a fall. She conveyed for the room her experience of living in fear, living under the persistent risk of facing a health crisis and having no one there to help. This was for me the beginning of a sense of unease that stayed with me to some degree for the entire duration of my field work, and perhaps continues to stay with me today.

Shortly after ʔiihmisuk had shared her story, the meeting convened for lunch. I asked her what she would like and if I could get her a coffee. I had a difficult time hearing her request, and, as it turned out, I had not brought her the right order. I wavered for a moment, a little embarrassed and unsure of how to proceed. A young council member for one of the northern Nuuchahnulth nations – and as I would come to learn, a key advocate for improving health services – stepped in to say, “It’s okay, I got you nan!” As an outsider, I was a little surprised and amused with the fact that the Elder who had shared such a profound story about the fear associated with isolation had relatives in attendance.

During my time at the NTC, I continued to hear pieces of ʔiihmisuk’s story as shared by her numerous extended family members dispersed across Vancouver Island, as well as through the ongoing communication between members of the NTC health department. As time passed, I heard news of her health scares, and the ongoing frustration every time her needs fell through the cracks of the health system. I also came to learn that she was now living in a care home in Port Alberni, much to the dismay of her family in the northern region. Throughout her journey, ʔiihmisuk remained forefront in the minds of her family members and of health care providers at the NTC who had come to know her. For me, this was an indication that she was never truly isolated.

However, ʔiihmisuk's story points to larger tensions which I address: the ongoing sense of abandonment²⁸ from crucial public services that co-exists alongside profound relational forms of care that simultaneously challenge, enhance, and are marginalized by biopolitical standards of care. In exploring this tension between modes of care as having the potential to be both exclusionary and relational, I draw from ethnographic examples of health inequity as a form of structural violence, giving shape to a political economy which makes relational modes of care impossible in some situations. In this chapter, I address access to health services, including primary and urgent care, in remote communities, as well as the historical and political structures that inform inequitable access to services as a structural violence. Indigenous peoples in western Canada are faced with systemic inequity in terms of access to health care and health outcomes; this is linked with the history of colonization and shaped by anti-Indigenous discriminatory discourse, which also reveals the necessity of Indigenous self-determination over health care delivery. Indeed, Indigenous governance over health services can mitigate many of the social determinants of health that exacerbate health inequities. I also emphasize that access to and quality of care must be understood as two inter-related dimensions of equity, which are both rooted in the colonial history of Canadian health services and

²⁸ My investigation of institutional abandonment both draws and departs from anthropological explorations of social abandonment. I am influenced by the ways scholars have demonstrated social abandonment to be an inherent function of neoliberal governance – the sacrifice of those excluded from the body politic is made to benefit those belonging to the body politic (Povinelli, 2011). For example, Biehl demonstrates how social abandonment sustains the middle class through the alienation of individuals who cannot care for themselves; ultimately deepening inequality in Brazil (J. G. Biehl, 2005). I depart from these works in the sense that I find they treat kin and families as simply the product of neoliberal values which negates the autonomy enacted in families (Han, 2013). Instead, in this chapter I focus on the justifications underlying belonging and abandonment from public health services. In later chapters, I explore relational care as a response to the affect of abandonment associated with living in the context of health inequity.

broader society. As such, access to services must not be overlooked as an inevitable consequence of living remotely but must be regarded by decision-makers as a key site for addressing the health disparities faced by Indigenous populations.

Throughout this chapter, I reveal access to care in remote communities as a structural exclusion informed by a mode of institutional care developed through the history of settler colonialism as it relates to the development of health services in Canada. Developing a critical understanding of the normalization of exclusionary modes of care is necessary to understanding the pertinence, impact, and influence of relational modes of care. Relational modes of care certainly existed within Indigenous communities before and alongside the colonial development of healthcare services in Canada but understanding how these modes of care co-exist today is a key step towards decolonizing health care for the benefit of Indigenous patients and healthcare providers. This is a task I address in various ways in each chapter. However, my initial goal is to unpack how social exclusion has become a normative mode of care, firstly by exploring how services are made available to remote Nuuchahnulth communities, and secondly how discrimination has come to factor into healthcare encounters (to be addressed in the following chapter).

Presently, British Columbia sits at the epicentre of major shifts in Canada towards Indigenous self-determination and recognition of the manifold forms of oppression faced by Indigenous peoples. Extensive research on social determinants of health quantifies disparities in health status as well as how they relate to Canada's colonial history. However, although the health disparities faced by Indigenous peoples "have been linked to social and economic marginalization (the social determinants of health), we have a limited understanding of the mechanisms that have created and now sustain these

conditions” (Brown et al., 2012, p. 46). Firstly, I contribute to this discussion by moving beyond measuring and defining what inequity looks like to harnessing ethnographic and narrative approaches to understand how and why health inequity persists in Nuuchahnulth communities, and the tangible effect of living alongside inequity. I then draw from a critical historical accounting of the development of health care services in Canada, paired with an application of theoretical frameworks that engage with structural violence, social suffering, and biopower. Drawing on these influences, I interrogate the socio-political processes that produce a logic of care that operates as a form of exclusion via the normalization of bureaucratic indifference. I conclude with two ethnographic case studies drawn from my research in remote Nuuchahnulth communities that demonstrate the interconnection between settler colonialism, dispossession from land, and health inequity in the form of inadequate access to emergent and primary care.

Defining Health Inequity

Health inequities are generally understood as differences in health indicators between different populations (often defined by age, gender, income level, nationality, and so on), as resulting from social and economic policies and practices. The emphasis on *inequity* in place of inequality or disparity is intended to highlight that inequities arise from situations which are “avoidable” from a policy perspective and are rooted in particular social conditions, including “social norms, policies and practices that tolerate or actually promote unfair distribution of and access to power, wealth and other necessary social determinants” (World Health Organization, 2008). According to the BC Patient Safety and Quality Council (BC-PSQC), equity is defined as the “fair distribution of services and benefits according to population need” (BC-PSQC, 2020). As such, inequity offers

an apt framework for examining differential access to health care, by evoking how these experiences “stem from long-standing, historically mediated disadvantages such as systemic racism and discrimination, the intergenerational effects of residential schools, welfare colonialism, and economic marginalization” (A. J. Browne et al., 2011, p. 334).

At this current juncture, the lack of services available to First Nations communities in BC is neither unexamined nor under-theorized. Indeed, the topic has become a focal point in health policy. The *Canadian Community Health Survey 2000-2001* indicated that access to a regular physician is much less common than the national average and that 20% of Aboriginal people indicated that they did not receive needed health care, comparable to 13% nationally. According to the survey, this was due to unavailability, inaccessibility (due to cost/transportation), and unacceptability (due to the attitudes of health care providers and/or competing responsibilities) (Waldram et al., 2006, p. 229). The more recent *First Nations Regional Health Survey 2015-2017* identified lack of access to health care as a key priority for the Vancouver Island Region. As the report states, “according to a BC Coroners’ Service and FNHA report, many First Nations youth and adults who died unexpectedly from 2010-2015 faced barriers when they sought care” (First Nations Health Authority, 2019, p. 69).

The gravity of this situation extends well beyond the province of BC (Goa et al., 2008; Peiris et al., 2008). For instance, Shah et al. (2003) demonstrate that Indigenous communities in northern Ontario face lower access to primary care, based on a higher admission rate for ambulatory-sensitive conditions (conditions that could have been treated in an ambulatory setting, such as a walk-in clinic). In other words, their research demonstrates a higher rate of hospitalizations and resulting complications for conditions

that could have been treated by timely access to primary care. In another study, Browne et al. indicate that in British Columbia, “the age-standardized mortality rate (ASMR) for ‘medically treatable diseases’ (meaning those for which mortality could have been avoided through appropriate and timely health care intervention) has fluctuated between 2 and 5 times higher for the status First Nations population compared to other residents” (Browne et al., 2011, p. 335).

However, statistics provide only a partial picture of the situation. In her work with low-income neighbourhoods in Delhi, medical anthropologist Veena Das aptly states that how life with disease is lived varies greatly between neighbourhoods and regions. Das’s work reveals how access to medical facilities, public spaces and work environments contribute to how individuals live with affliction (Das, 2015). Similarly, an examination of access to health services can reveal that inequity is felt not only in elevated prevalence of chronic illness, but through the avenues available to determine one’s own life lived with disease. Statistics also cannot account for what has been lost in terms of quality of life and the significance every individual holds to their community and family. A Hesquiaht Elder whom I visited described to me her experiences being raised by her grandparents, who lived to be well over 100 years old. Another Elder in Ditidaht shared about his grandmother who lived to be 109 and his grandfather, a fur sealer who worked near Haida Gwaii, who lived to be 111. Indeed, several Nuuchahnulth Elders recalled the days when the older generations lived well into their 100’s, often attributed to a combination of lifestyle, immersion in culture and eating wild foods. When juxtaposing these stories with, for example, current life expectancy statistics, it reveals a narrative of change and loss that permeates how we may think of health and health services.

In this and the following chapter, I will examine two dimensions of health equity: accessibility and the socio-affective dimensions of health care experiences (what will be discussed as culturally safe, dignified, and/or relational care). According to the BC-PSQC²⁹, quality health care can be understood via seven dimensions that address individual and population health, as well as health delivery systems. These include: respect, safety, accessibility, appropriateness, effectiveness, equity, and efficiency (BC-PSQC, 2020). Each of these dimensions of quality are to be understood as compounding or complementary in that if one dimension fails to be met, it is likely to affect other dimensions. I mention the recent Quality Matrix developed by the BC-PSQC because the turn towards a more integrated view of health care quality acknowledges Indigenous understandings of wellness and the influence of socio-cultural aspects of health care experiences such as respect and appropriateness of care on health outcomes. I find this to be a pertinent move, as there is a pervasive tendency to compartmentalize cases between either an instance of blatant racism, or an example of unfortunate circumstances due to a strained health care system – creating a situation which is impersonal, and therefore “not” an example of discrimination.

For example, in January 2019, I chaired a meeting in the NTC Health Department between NTC nursing management and health leaders from two of the Nuuchahnulth Nations. We had met to discuss an upcoming action research project to enhance cultural safety across health systems by addressing the lack of collaboration between health

²⁹ The BC Patient Safety and Quality Council (BC-PSQC) Quality Matrix is the standard for health care delivery across the province.

systems and persistent experiences of discrimination. This discussion evolved into a roundtable discussion of poor experiences in the local hospital. Later in private, an external collaborator remarked to me that many of the issues raised are not about cultural safety but weaknesses of the health system that affects all patients in the same way, poor organization and a lack of primary care. At the time I agreed, and it is certainly true that poor organization and a lack of primary care negatively affects the health of all Canadians. But these issues are not experienced in the same way for all peoples living in Canada.

What I wish to emphasize is that the more socio-cultural dimensions of health care experiences such as respect and appropriateness (or how these attributes may variously be defined as cultural safety, relational care, anti-discriminatory, and so on), cannot be examined in isolation from access to health care. Both the lack of quality and accessibility of health care services factor not only into health disparities faced by Indigenous peoples in Canada, but also into individual healthcare experiences as potentially discriminatory or even traumatic. Thus, I emphasize that it is problematic to discriminate between stories expressing limited access to health services within an impersonal and limited health care system, and experiences of poor-quality care as an example of discrimination. Rather, both limited access and poor-quality health care need to be understood as compounding dimensions of discrimination within the health care system, and as a pervasive legacy of Canada's colonial history.

The concept of health equity – a discourse with established traction in international and national public health policy – offers a helpful lens for understanding both access and quality of health care available in Nuuchahnulth communities because

both are due to “avoidable” conditions of care, which can be remediated through decolonizing health systems and healthcare delivery models through community control of health services. Importantly, bringing both quality of, and access to, care under the umbrella of health equity affords recognition to the probability that “while some experiences of discrimination may be interpersonal and obvious, they are also likely to be institutional and invisible” (Krieger, 2000, p. 43).

“There is no help”

It feels like people are worried because they couldn’t get the proper care that they needed. I think there are [barriers to accessing health care in my community] but I don’t know. It just depends what it is and then if there is someone out there that’s going to be there to help you instead of having to say, “Oh, there is no help” (Yuulu?i?ath Elder, interview, April 16, 2018).

In the context of this work, I observed that community members and NTC nurses experienced health inequity as a pervasive sense that “help” (from the health care system) was not available. This resulted from a lack of access to primary and urgent care in Indigenous communities and ongoing discrimination within the health system. As a result, NTC nurses spend a considerable amount of energy supporting families to advocate for loved ones, whether for necessary medical devices, home care, or counselling, among a number of other frequently unmet needs. Here, I outline the lived realities of inequity regarding access to primary care³⁰ in remote communities, especially in terms of care for older adults living with chronic disease, and medical travel.

³⁰ By primary care, I refer to the first point of contact for a patient seeking preventative or curative medicine, including diagnostic tests, referrals, and prescriptions.

Access to primary care, as a facet of health inequity, intersects with place and social geographies as sites of exclusion. The experiences of living in a remote community, closer to town, or for those living away from home each present their own specific challenges. While I touch on some of the salient issues, I also recognize that the divergence between experiences warrants additional focused research and discussion to better understand how to address the current inequities as they manifest in particular sites. For instance, for Nuuchahnulth nations located close to municipalities, the most salient challenges to accessing health care include a lack of urgent care clinic hours, a dearth of family doctors accepting patients, long hospital wait times, and pervasive accounts of discrimination. Nuuchahnulth-aht living in town face specific challenges around what health services they are entitled to, often caught between not having access to health programming or medical travel funding made available to members of the nation living on-reserve, while also being excluded from or discriminated against within services offered by the regional health authority. Compounded with this, it is also important to recognize that access to health care and health care experiences are influenced intersectionally through other social markers such as gender, age, ability, and health needs. While keeping these complexities in mind, my focus here is more specifically on access to care in remote communities, such as those accessible by boat or logging roads.

“Remote” is a concept I define and unpack as part of a logic of care which legitimizes the exclusion of some populations from what is generally considered as a public, universal good. However, “remote” also offers an important descriptor of social and geographic spaces, and the term is commonly used both within the NTC and health policy. Within the context of the NTC, remote communities are identified as being

communities that cannot be accessed by a paved road. The term is also used to emphasize some of the more extreme experiences of exclusion from health services. Within the regional health authority, smaller municipalities or townships are categorized as being, in order from most to least accessible, “outlying rural,” “remote rural,” “accessible island,” “very remote rural,” and “isolated island.” These categorizations inform scheduling, staffing, and funding of public health care as managed through the regional health authority.

Figure 4: A map hung in the Gold River Health Clinic identifies communities through rural, remote, and isolated codification. June 2, 2019.

Health services in remote communities are often provided only through a nursing post, or by fly-in visits from locum physicians. As such, First Responders (trained volunteers living in the community) are key providers of urgent care in remote villages and hold a respected role in remote communities. However, as a volunteer position, the number of First Responders in a community fluctuates over time and it is not uncommon

for someone to experience a serious injury at a time when no responders are available in the community. When discussing this topic, a Ditidaht Elder, laughed that “yes, [we have a first responder], but he lives in Port Alberni and his ticket expired!³¹” Further revealing the gravity of a reliance on volunteers for urgent care, Čaatčaata, a Ucluelet Elder, described his struggle coming to terms with some of the traumatic scenes he has witnessed in his role as a First Responder. Čaatčaata had spoken to a doctor about his concerns with his mental health and was offered a prescription for antidepressants, which he declined. He criticized the lack of critical incidence stress support available for First Responders, such as debriefings led by psychiatrists or counsellors who could support responders in processing and recovering from a traumatic event. As someone initially unfamiliar with life in a remote community, I was shocked to learn that those holding a position akin to a paramedic would not be formally supported in their work (or for that matter, compensated).

Along with First Responders, Nation staff including Health Directors, Community Health Representatives (CHRs), and Medical Travel Clerks also play key roles as gatekeepers to the health care system and as mediators effectively negotiating health policy and harnessing resources to meet the health needs of their communities. Healthcare providers with the ability to prescribe and diagnose are not, at the time of writing, employed by the NTC or First Nations. How often healthcare providers were available in remote communities continually fluctuated between communities and over time. In general, a locum doctor or nurse practitioner could be present within the remote

³¹ First aid certification expired.

communities from between once or twice per month, to weekly appointments. However, remote communities often face periods of time with no prescribing health care providers travelling in for appointments. The NTC Health Department was continually engaging with the regional health systems and health care providers to ensure Nuuchahnulth have more consistent access to primary care in the communities. As a result of such unpredictability, NTC nurses are challenged when recommending a client to follow up with a physician for a particular health concern when they cannot offer any guarantee of when one might be available in the community.

Furthermore, NTC nurses explained that the limited number of hours doctors have available in the communities is rarely enough to meet most patients hoping to be seen. In the case of Huu-ay-aht and Ditidaht, both communities are about a two-hour drive from the nearest town on an unpaved and often dangerous road. Families living in these communities, when faced with a health concern, must decide whether to arrange for the travel, or wait until a health care provider visits the community. However, with highly unreliable schedules and often not enough time to serve all patients that are waiting, it is unrealistic to rely on the locum doctors who travel to remote communities. NTC nurses also found collaboration with physicians challenging because of the unpredictability of their schedules. While the NTC nurses are often able to offer more frequent and consistent visits, they are limited by their scope of practice as well as the time they have available.

Concerns voiced in the communities about the availability of health care providers also extended to the NTC nursing services. NTC nurses identified that one of the biggest barriers they face in their role is having the time available to meet clients

requesting visits, especially for those with complex needs. Some community members expressed that they felt the NTC nursing services greatly enhanced access to health care within their community. However, many other participants, particularly individuals living in the northern region, expressed that they were dissatisfied with the NTC because they felt they were not present or available often enough within their community.

Overwhelmingly, there was a wish expressed that basic primary care, medical supplies and individuals trained in first aid, be available in communities. It was emphasized by both community members and NTC nurses that increasing staff availability is crucial not only to be able to provide adequate services, but also to provide relational care. Rotating doctors in remote communities means that people do not have access to a regular family doctor that they can follow up with or to build rapport. As a result, some individuals find doctors in town, but the cost and time required to travel is a barrier for many.

Tuupšił, a non-Indigenous NTC nurse, shared her thoughts about why it is so crucial to have the same healthcare staff serving a community over the long term:

Tuupšił: We're talking two to three years of building that relationship and having them trust that you're there for the right intentions and you're not just a nurse that's a fly by nurse coming and doing medical work and everything. So really trusting that you're going to stay and be there.

Megan: It must be really difficult when there's new nurses coming in or like when people are switching positions.

Tuupšił: It is. And it's hard on the community too. And it does happen even within our organization. They'll move nurses around. Just recently, we had one of our homecare nurses moved from Port Alberni to the coast. So [another NTC nurse] got taken out of her community that she's been in for 10 years [due to staffing shortages]. So, that's really hard when our whole framework is built on relationships and knowing people, and now you're starting all over again. (interview, December 7, 2017).

Tuupšił's comments reveal how the structure of health care (in this case, the funding and incentives at the disposal of the NTC to retain staff) imposes limitations to relational care which forces management to prioritize staff coverage over relationships between nurses and the communities they work with. Health inequity in the form of lack of access to primary care often places front-line staff, management, and clients in the position of making zero-sum decisions, where something must be sacrificed in the face of addressing a more pressing need. The choice of NTC management to maintain coverage at the expense of patient-caregiver relationships is one. For patients, considering whether to travel from remote communities to seek medical attention often presents another.

Medical Travel

Nuu-chah-nulth-aht living in remote communities face a particular challenge in accessing primary care and specialist appointments, due to the cost of transportation. Support for travel for medical appointments or emergent care is provided from the federal government through First Nations on an as-needed basis. Many contributors remarked that this is an essential service, especially for individuals who are low income or do not have access to a vehicle. Hasp'iqak, a health leader from the northern region, shared her perspective on the limitations of the current medical travel support program:

Right now, not everyone has a boat and a vehicle. Getting to appointments is... filling out paperwork, just to get to appointments. You have paperwork you have to fill out; paperwork you have to bring back. You have to arrange the water taxi. You gotta arrange a ride from fair harbour to Port McNeil or Campbell River, Nanaimo. And when you're dealing with end of life or things like cancer, then you're going to Victoria. So, some of those barriers are the only escort that is covered is only covered for like a day (interview, March 15, 2018).

Travel out of community for emergent care or specialized appointments requires the ability to cover personal expenses for accommodation, parking and meals (at least until travel funding is reimbursed), as well as an ability to manage the travel logistics (often requiring multiple modes of transportation) and required paperwork, all amid a family crisis.

Contributors commented that travel funds available were not always sufficient for the amount of travel required for individuals or families travelling from remote communities (i.e., funds for overnight stays). In the case of many remote communities, attending a morning appointment requires overnight travel. A young woman living in Ehattesaht First Nation commented that:

Before I moved, we would not get our patient travel money for our food and money for our fuel to go that way and come back home. Like we wouldn't even get it until the day after we came back from our appointments. And now, they really do help but not as much as they can be. We only get seventeen dollars for a meal. And with the way gas prices are nowadays, we only get like eighty dollars for fuel. And that's enough for like a ride from here to Woss, pretty much. Or at least to Sayward. But like so many people have kids nowadays, it's like, what's seventeen dollars going to do for food? And so many people go out there and they pretty much starve when they go because they don't have enough money for meals (interview, June 28, 2018).

Most concerning is that individuals may miss appointments as a result of inadequate support for medical travel. Āix^watin, an Ahousaht Elder living in Port Alberni commented that:

They have difficulty accessing, or they're not really following up with their health needs and they get really sick. And that's where this access to medical travel affects. The people who really need it really can't access it. So, they don't bother. They miss their important appointments. (interview, February 15, 2018).

In addition to remote communities, many reserves near towns and cities also do not have adequate transportation available to and from reserves. Related to the challenge of travel,

especially within remote communities, both nurses and community members identified a barrier in terms of accessing prescription medication. Additionally, there are physical challenges associated with travel, especially for those with mobility challenges or in recovery from an injury or surgery.

Figure 5: View of Opitsat from the air, December 12, 2017

Elder Care

In speaking with individuals living in remote communities as well as the Nuu-chah-nulth nurses serving remote communities, a key concern was the availability of care required for Elders with health concerns to live comfortably at home. While many of these issues are found in non-Indigenous communities, for the Nuu-chah-nulth they are amplified, given the layered forms of colonialism, racism, and discrimination from institutional systems and the history of rights-based mobilization of Indigenous people in Canada. A significant concern was the possibility of an Elder having a fall and not having immediate help. This also relates to the long wait times for referrals to occupational therapy which could provide medical equipment or adjustment to their homes which could make living independently safer. Other care needs included housekeeping, meal preparation, shopping, and regular social visits. While responsibility for care is typically shifted to relatives (by both health systems and families themselves), it can be difficult for relatives to meet these needs while working or caring for their own children. For example, Nunuukma, a young woman living in Ehattesaht, explained that:

I think a lot of [Elders] need reminders, like their medications. ‘Cause like with my family, like I try and help as much as I can but there is still sometimes where my grandparents aren’t getting enough help . . . Like so much Elders have diabetes and so much Elders are getting cancer. They are neglected and abused (interview, June 28, 2018).

My impression of how these concerns were voiced was of expressing experiences of injustice; that there was an inherent unfairness to the arduous travel and bureaucracy involved in order for the ill or elderly to access needed care. This is something I felt both community members and NTC nurses gave voice to in their conversations with me. To provide an example, Nunuukma shared an account that illustrates her own experience of

loss as a result of inadequate access to emergent care, as part of a larger narrative of injustice and grief shared among members of remote communities:

They are constantly on social media saying how sad it is for them to see their Elders to have to go through that because they have to take them either across the water or send them all the way down to Fair Harbour to get them shipped out to Port McNeil. Just to get the help they need. Like it's so dangerous, too. So scary. Like especially when it's like a serious injury and they are needing a doctor. I think it was like two or three years ago now, my great grandma was getting shipped from Kyuquot to Campbell, and because of how fast they have to drive in an emergency, the roads were icy, and they went off the road and we lost my grandma. And a paramedic, I think. It's not easy to live here. But it's not that easy to leave either. (interview, June 28, 2018).

By emphasizing “it’s not easy to leave,” I believe Nunuukma was touching on a sentiment shared among several participants that choosing to live in risk is a commitment to living in connection to territory, as well as renewing community cohesion. Many community members living in remote communities lamented that sending Elders out of community to live in care homes was a substantial loss to the community, both in terms of maintaining strong family structures as well as a loss of cultural knowledge. As such, the injustice regarding inadequate access to services is felt not only as differential treatment based on place and race, but also as an assault on Nuuchahnulth ways of life and governance. Inadequate access to care is experienced through the separation of families as a means of fragmenting communities as they persist in connection to *ha’hoolthi* (traditional territory) and the *hahuupa* (wisdom) embedded there. Considering this, we may simultaneously think of inequitable access to primary and urgent care as entailing multiple layers of structural violence, implicating social and spiritual as well as physical wellbeing.

In March 2018, I had coffee with ʕay’ama Nuči, a nurse who had served many of the northern communities in various capacities for several decades. At a quiet table in the only café in Gold River, ʕay’ama Nuči and I sat together with my daughter pacing the room, as she shared several revealing stories. Reflecting on a recent experience, she expressed her frustration in coordinating hospital discharges into a remote community after a surgery. She explained that hospital staff do not seem to understand the risks and extensive planning required for a patient living in a remote community to return home, in terms of travel and available home care.

Clients are sent home with like no notice. Or like a day’s notice that we’re discharging somebody. . . we get people discharged to Kyuquot and Zeballos. We are not ready for that. “Oh, they just need dressings every other day so they can go home.” Well, who is going to do that for God sakes? And the other thing that happens then, is that their service, they got sterile trays, and sterile everything, right. And we’ve got disposable equipment, but in an environment where the best you can do is keep the cat out of it, I mean that’s the best you can do. And it’s not like we’re not trying, but they don’t teach you this at nursing school either, that there are ways to do things, or how to manage when you can’t manage (interview, March 27, 2018).

ʕay’ama Nuči also shared a dramatic example of how the decision to stay in the community or take on the risk and expense of travel can sometimes play out.

We had to send somebody out once on a holiday weekend. And I go into this house and I see this mom who’s pregnant, and she’s sitting on her hands like this, rocking. And I’m going “Shit! She’s going to deliver!” She’s in labour and this isn’t her first kid, this is like kid number 5, I think, four or five. And so, I say, “You have to go,” and she says, “We have no money,” you know, “We can’t go out, we have no money.” And I thought, “Well you have to go. This isn’t an option; you have to go.” And so, I go to the band manager and I say, look these guys have got to go out because I said her last one was a C- section, so if she delivers now, she could blow, she could die and the baby could die, if she ruptures her uterus. And I said, “and she’s in labour!” . . . And so, they get the money and they get it together and she’s out of the community but, if I hadn’t gone there, she could have died having this

baby, or trying to get out of the car and having it on the road in Zeballos³² (interview, March 27, 2018).

In considering the origins or cause of inequitable access to health services, there are several likely factors at play in the above scenario: poverty and cost of transportation, or past encounters with the health care system, among other invisible considerations. However, what this narrative does demonstrate is that the barriers Nuuchahnulth people living in remote communities face in accessing health care places individuals at an immense and unnecessary degree of risk.

Similar stories were expressed to me of Nuuchahnulth people embarking on the long and expensive journey from remote communities to seek acute medical attention, only to have their health concerns dismissed and left untreated. In my conversation with Łay'ama Nuči, it seemed she had encountered innumerable cases of complications and unnecessary suffering resulting from lack of access to care. To provide another compelling example, she shared with me a profound sense of disappointment when a family she was supporting was turned away from accessing health services:

We had one person from Ehattes, that their fourteen-year-old was burned in a fire. And so, we needed a few of the compression garments, a jobst suit . . . So, they and their four kids, one of them is a baby, pack out of Zeballos at the end of the day because mom's working. Mom's working, they can't be without mom's money. So, mom's working, so they drive all the way to Victoria [450 kilometers, including logging roads]. They get to Victoria about two-thirty in the morning, you know three o'clock in the morning, that's when they get there. And then they have to be at Royal Jubilee [Hospital] at nine AM. Well, they fell asleep, and they slept through it 'cause they're exhausted. And so, they called and said, "Can we change

³² In remote communities, it is common practice for mothers to be sent to stay in town during the last trimester of their pregnancy. As such, the right to birth at home has become a site of contention for many Indigenous women (Cidro et al., 2020). I do not have insight as to whether staying in community during late term pregnancy is a deliberate act of defiance towards the policy of forced evacuation, a result of not having the means to afford travel and accommodation away from home, or simply due to the unpredictability of life. However, it does seem to be common occurrence (Titian, 2019).

the appointment?” They went “No, you’re fifteen minutes late we canceled it.” And I called them, and I said, “What the hell! They would have waited, you know, if you’d told them to just come in, cause I’m sure you get breaks during the day, they would have waited all day to get this garment. Instead, you told them, no, you canceled it.” They’re already tired, so they swear at you and then you go, “I’ve had enough”, you know, piss off. And so now they go all the way back to Zeballos with no jobst suit on this person. So now I’ve got this young man who’s got no compression garments because the system wouldn’t accommodate them or help them (interview, March 27, 2018).

This case illustrates a standard practice: when a patient is late for an appointment, their place is taken by the next patient in a busy and over-burdened clinic. Yet such protocol fails to take into account the extent of investment made by the family to attend the appointment and the socio-material context of employment and care for children that delineates how they are able to access the services. By coming to understand the lived reality of traveling for days with children in tow to seek support in a time of crisis, the question of why care was not obtained becomes less so a matter of responsibility on the part of the parent, or their worthiness to hold that appointment, and more a question of why compression garments are not more readily available. In my own interpretation, it seems unrealistic to expect any family to be exactly on time and perfectly composed given the gravity of their situation and the inordinate amount of effort and resources required to seek care for a burn victim.

This example illustrates how distribution and availability of medical services is based in normative colonial ideas of the centre and periphery. These normative ideas are so embedded within the health care system, that bureaucratic modes of care do not allow space for the experiences of these living outside of its normative centre. Reflecting this sentiment, Našuk, a Uchucklesaht Elder who had in recent years chosen to move from her remote community of Kaldonen, shared her thoughts on how the situation has improved

through the instatement of Nuu-chah-nulth controlled nursing services. Over a pot of tea in her home in Port Alberni, she explained:

The NTC nurses represent patients and have knowledge of our culture. They don't judge. They never forget, they always come back. The way it used to be Elders died on reserve because they couldn't get help soon enough. Now NTC will help. My grandmother fell and had no way to get to town. She screamed and cried all night. She was sent into the hospital the next day, but it was too late, she died in the hospital from a broken hip. Now we don't have that same fear anymore. NTC has made a huge difference (interview, June 21, 2018).

In the context of inequitable access to primary care, self-determination of Indigenous nations over health services is not just about political emancipation. It is about replacing oppressive or indifferent health services with relational care. It is about the resilience of community togetherness, territory, and culture, as key facets of individual wellness.

Ultimately, and more immediately, it is about saving lives.

Inequitable Access to Health Care as a Systemic Violence

In the supposed era of reconciliation and the acute awareness of colonial violence historically associated with healthcare in western Canada, how are we to make sense of a health system that continues to exclude and marginalize Indigenous peoples? When there is a consensus on the nature of wrongdoing, why does it continue to be so challenging to do health care delivery differently? Writing in such a fraught context, I conceptualize of disparities in access to health care as a systemic violence. According to physician and anthropologist Paul Farmer, structural violence is systematic, embedded in the social order and enabled by the erasure of historical memory (Farmer, 2004). Farmer suggests that an anthropology of structural violence requires making visible the suffering that is excluded from dominant narratives. This in turn requires sustained focus on the

materiality of the social--the lived consequences of violence including epidemics, human rights violations, discrimination, or health inequity.

Social theories stemming from social suffering and biopolitics offer an avenue for theorizing the logics of institutional care and health systems which structure and justify social exclusion. Social suffering examines how political and economic power produces suffering or shapes the institutional responses to social issues (Kleinman et al., 1997).

The anthropological focus on social suffering was influential at the time of its inception, however the framework alone accomplishes little beyond shifting the lens through which anthropologists (and ostensibly a broader public) make sense of experiences of illness³³. That affliction has a socio-political foundation is presently accepted well beyond the field of medical anthropology and has indeed become a standard mode of assessing health systems and interventions – through concepts such as equity and the social determinants of health, among others – in public health and international health policy. What I find is

³³ Although aiming to critically interrogate cultural representations of suffering, much anthropological writing in this area actually works to fetishize suffering (Robbins, 2013). As such, social suffering becomes an object of fascination under the anthropological gaze by way of interrogating local metaphorical representations of pain for meaning. I am in agreement with Scheper-Hughes that such approaches can be dangerously close to producing theodicies, in which “attempts to make meaningful the suffering of others, is the risk of normalizing and accepting the suffering and death of the other” (Scheper-Hughes, 2007, p. 199). This approach turns away from interrogating the structures that make suffering a part of any local world. Furthermore, I am writing of health inequity and social suffering in the context of a long history of research which pathologizes Indigenous peoples, or constructs Indigenous nations as passive victims of development, lifestyle changes, or the spread of disease (Kelm, 1998; Waldram et al., 2006). Writing alongside this historical tendency reproduces a complicity towards colonial oppression by justifying paternalistic interventions and downplaying the resilience and perdurance of culture and governance within Indigenous nations. Yet to remain silent is also to remain complicit with oppression. As a non-Indigenous scholar, I am particularly culpable towards reproducing the things I wish to speak against. My approach in this difficult space is to focus my interrogations on the justifications and explanations of why things are as they are, rather than interrogating the experiences of pain themselves. As I explore in later chapters, the pain of others presents a limit to intersubjectivity which I believe always should be acknowledged but not exploited through the western scientific compulsion to know or to possess through the acquisition of knowledge.

needed to extend these insights is an in-depth understanding of how and why an ostensibly universal public good such as Canadian health care continues to operate through the exclusion of Indigenous peoples – both through limited access to primary health care, as well as through more overt discrimination - and how this is silenced or legitimized through the structure of health services in Canada.

A relevant aspect of Foucault's formulation of biopower is that at the same time it claims to protect and promote the vitality of a population, it is also inherently exclusionary. For Foucault, biopower is structurally racist. As interpreted by anthropologist Lisa Stevenson, "the sovereign right to kill re-emerges in modern society through the "tactic" of racism, a form of binary thinking that separates society (understood to be structured by biopolitics) into those who deserve to live (and have life protected, extended, and amplified) and those who deserve to die" (Stevenson, 2014, p. 195). Thus, biopower as exclusionary, wherein racism is the mechanism of and justification of exclusion, operates under the premise that the exclusion of some sub-populations allows for increased vitality of the population at large (Foucault 2002).

Previous anthropological studies on institutional structures of care often identify how care can become entangled with neoliberal or biopolitical logics of exclusion, affording resources and services to populations defined and identified as deserving (Biehl 2013; Ticktin 2011; Povinelli 2011; Fassin 2011). For example, Elizabeth Povinelli has extended this framework to critiquing the exclusionary tendencies of institutionalized care by stating that "in neoliberalism to care for others is to refuse to preserve life if it lies outside market value" (Povinelli, 2011, p. 159). Drawing on the concept of biopower in addressing suicide care in Inuit communities, Stevenson suggests that the "logic of

biopolitics rests on the suppressed idea of an inferior population” (Stevenson, 2014, p. 119). Stevenson’s contribution illuminates how what she terms “the psychic life” of colonialism can manifest within mechanisms of biopower in institutional structures such as health care through attitudes, forms of governance, and modes of conduct (Stevenson, 2014). She describes this “affective valence” of colonialism and biopower as producing “indifferent” or “a-nonymous care” (Stevenson, 2012). In an indifferent mode of care (such as in tuberculosis sanatorium), life is to be preserved at all costs, but only because it is the obligation of politicians and doctors to do so, not because of who those individuals are. She states, “when life become an indifferent value, it no longer matters who you are – simply that you cooperate in the project of staying alive” (Stevenson, 2012, p. 601). Additionally, “to care anonymously also requires being able to care intransitively” (601) not exactly for the person, but for their bare life (Stevenson, 2012, p. 601)³⁴. I find that Stevenson’s formulation is insightful, however it fails to reconcile why “indifferent” care can manifest as differential or exclusionary for Indigenous populations. I find Farmer’s structural violence informative as a way to describe bureaucratic indifference as a

³⁴ Stevenson’s approach to Inuit-state relations draws very heavily on Giorgio Agamben’s work on holocaust in Nazi Germany (Agamben, 1998). Agamben is also interested in the relationship between biopower and state sovereignty, by addressing the politicization of “bare life” in western democracies. Agamben argues that biopower and sovereignty are integrated rather than separate historical moments as suggested by Foucault. Agamben questions how the obligations and actions of modern states can shift from preserving biological life to destroying it. For Agamben, a bare life is “a life that is always already exposed to an anonymous death” (Stevenson 2012 p. 598). This occurs within “states of exception”, which through a declared state of emergency, states can act outside of the rule of law presumably as a public good. Agamben claims where genocide occurs, these states of exception have become normalized, or have become themselves the rule of law. Agamben’s adaptation is useful in understanding biopower as an inherent potential for violence, however I find that Wolfe’s analysis of genocide in the United States (Wolfe, 2006) more applicable in this context, in the sense that genocide or a “logic of elimination” is a process rather than an event and is inherent to settler colonialism.

blindness to historical memory or the shaping of discourse that works to ignore, downplay or even justify the systemic causes of health inequity.

In attempting to extend anthropological approaches to social suffering, I turn to Gee and Ford's description of systemic racism, in that "key characteristics of structural forms of racism include that they (1) persist over time, (2) adapt to new sociopolitical contexts as they unfold, and (3) impact population level patterns of disease more fundamentally than do proximal factors" (Gee & Ford, 2011, p. 124). This is also somewhat synonymous to Kurtz et al.'s structural violence, which includes racism, discrimination and acts of silencing. According to Kurtz et al., structural violence is linked to processes of colonialism which displace Indigenous values and beliefs (Kurtz et al., 2008, p. 55). As such, inequitable access to primary care in remote communities can be understood as a structural violence which encompasses far more beyond health, as a product of centuries-old historical processes embedded in the relations between Indigenous peoples and the Canadian state.

Building on Kurtz et al.'s dimensions of structural violence, including racism, discrimination, and acts of silencing, I add normalized bureaucratic indifference to persistent forms of suffering. In doing so, I draw from Foucault's biopower (and more recent adaptations of this concept) to interrogate the diffuse processes of governance that reproduce such indifference (Foucault, 2002). In interrogating why this structured exclusion persists in the present era of healing, reconciliation, and self-determination, a study of social suffering can reveal society's silence towards suffering, or as Kleinman et al. state, "how our usual practices of casting social experience as "natural" or "normal" obscure the greatly consequential workings of "power" in social life" (Kleinman et al.,

1997 xi). This silencing, or normalization of disparities in access to health care signifies a bureaucratic indifference, given the available knowledge of health disparities faced by Indigenous populations. Bureaucratic indifference was identified by Kleinman et al. as a key ethos of the era of modernity. Bureaucratic indifference is not just a malignant yet inevitable symptom of neoliberal governance, it is a politically motivated and rationalized commitment that is embedded in state structures. Here, I unpack the lack of access to primary care not as an inevitable consequence of living remotely, but rather as a condition of settler colonial and neoliberal state structures. In fleshing this out, it is helpful to reflect on the historical development of health care in Canada, and the institution of reserve lands, as two interrelated facets of the colonial project.

Colonial History of Health Care

Racially segregated health care is a shockingly overlooked historical fact in the consideration of health disparities in Canada (Meijer Drees, 2013). Legally ratified through the Indian Act of 1876, federal responsibility and resources were siloed between imposed racial categories such as “status Indian” and through the institution of reserves (Kelly, 2011). Early colonial health services were implemented in an ad hoc manner by missionaries and traders, facilitating the haphazard and jurisdictionally problematic structure of Aboriginal health services today (Lavoie et al., 2015; Waldram et al., 2006). From the confederation of the Canadian state until the mid-20th century, health services were managed by Indian Affairs and Christian Churches, and included segregated Indian hospitals, mission hospitals, and field nurses and doctors (Meijer Drees, 2013).

The provision of medical services by the Canadian state was supported by several agendas, including a humanitarian aspiration to relieve suffering due to ill health and a

fear of ‘the other’ as a site of contagion. In writing on the history of Aboriginal health in British Columbia, Mary-Ellen Kelm states that the ideal of medicine as a humanitarian project actually obscures power relations, as health services “also functioned as a legitimizer of colonial relations” (Kelm, 1998, p. 127). The development of biomedical health services served a colonial political agenda by managing the physical bodies of Indigenous populations and through the collection of data and the production of public health knowledge. As Kelm has outlined, “colonial governments appropriated medical power by encouraging the production of knowledge about indigenous bodies that justified racial hierarchies. The same medicine reified those hierarchies by providing segregated and inequitable services on the basis of race” (Kelm, 2004, p. 335). Furthermore, the provision of non-native medicine was intended to impress the Aboriginal peoples with its superior efficacy.

During the early 20th century, the Aboriginal population was pathologized, seen as incompetent and immoral, and thus to be blamed for their own health issues. This attitude infiltrated policy, as seen in forced evacuations and racial segregation in hospitals (Waldram et al., 2006). Despite the authoritative impact of biomedical health services, medical pluralism persisted, wherein traditional medicine and biomedicine simultaneously co-existed and were drawn upon by both Aboriginal peoples and settlers for various illnesses (Waldram et al., 2006, p. 151).

Colonial policies also impacted Indigenous bodies through nutritional changes. Reserve allocations imposed in the 1880s cut families off from the resources they had traditionally relied on, therefore limiting resiliency in times of scarcity causing starvation and mounting hostility (Kelm, 1998, p. 28). In fact, many reserve communities in BC

were alienated from water sources and had to lease rights to the water from the provincial government (Kelm, 1998, p. 30). As this historical accounting demonstrates, reserves as a site of exclusion extends beyond health to economic and political marginalization. In demonstrating the link between economic marginalization and loss of political autonomy as linked to health, Ćix^watin, an Ahousaht Elder, explained that:

Back in the '60s there was a lot of fish, a lot of trees. No, it was all taken away! Her dad [father in-law] was a commercial fisherman. My dad was a commercial fisherman. He travelled up and down the coast fishing, my dad travelled the west coast. So, our families were very independent. They didn't depend on the government (interview, February 15, 2018).

The Federal Indian Health Services were established in 1904. Though this department was filled with controversy over how funds should be spent, it did mark the beginning of publicly funded nursing stations and health education. However, the conditions were not permitting of quality services; "the Branch has never had at its disposal any more than about one-half the amount per capita expended by the Canadian population at large" (Graham-Cumming 1967:126 in Waldram: 193). Health services in the first half of the twentieth century were out of touch with life in Indigenous communities as centralized decisions were imposed from Ottawa. The mission of the federal government at this time was that:

Aboriginal health care was in crisis and the federal government considered itself morally responsible to correct and thus resolve "the problem" of Aboriginal people by promoting health, assimilation, eradication of traditional medical practices, and removing the threat of spreading epidemics to non-Aboriginal populations (Meijer Drees, 2013, p. 18).

Based on the colonial view that Aboriginal culture was incompatible with good health, the provision of health services became a focal point in extending cultural assimilation (Brown et al., 2012; Kelm, 1998). Stevenson has remarked that through health services

provided to the Inuit during the 1940s, particularly tuberculosis screening and evacuation to sanatoria, it was implied that “caring for the Inuit entailed eradicating the Inuit way of life” (Stevenson, 2014, p. 120). It has been widely demonstrated that the assimilation, racism, and cultural genocide within the mandate of the Canadian government is directly linked to the lower health status of Indigenous peoples in Canada (Kurtz et al., 2008; Peiris et al., 2008; Reading & Wien, 2013; Waldram et al., 2006). It is a terrible irony that an institution designed to alleviate affliction also operated under the same colonial imperative.

Between 1945-1962 the Indian Health Services replaced Indian Affairs in administration of health services offered for First Nations communities, when large and centralized institutions replaced community-based care (Kelm, 2004). The Nanaimo Indian Hospital is one such institution, with a focus on tuberculosis treatment, and offered 210 beds for Indigenous peoples spanning the west coast. Admission to the Nanaimo Indian Hospital was compulsory if a patient had a diagnosis of tuberculosis (Kelm, 2004, p. 339). Historians have noted that the existence of the Indian Hospitals was used as an excuse to shun First Nations patients from other health centres, since “given that Aboriginal patients had their fees paid at a fixed rate by the Department of Indian Affairs, the general hospitals at Prince Rupert and Terrace routinely turned them away for more lucrative non-Native patients” (Kelm, 2004, p. 339). However, by the mid 1960s, many Indian Hospitals closed down and “segregated care was no longer acceptable in the eyes of the Canadian public” (Kelm, 2004, p. 340).

During the latter half of the 20th century, the decline of infectious disease as well as the emergence of universal health care spurred a trend of devolving health care

administration to First Nations communities themselves, through the Federal Health Transfer Program (Meijer Drees, 2013). At the same time, the notion of Indigenous self-determination was gaining traction through increasing Indigenous mobilization occurring at both the national and international scale (Million, 2013). Over the course of the 20th century, the colonial mentality of Aboriginal health policy gradually shifted through the relentless pressures of Indigenous leaders advocating for recognition of rights including the rights to water, territory, and health services (Kelm 1998). It is important to note that the close historical tie between health services and the assimilatory mandate of the Canadian government is not to imply that Indigenous healing methods were subsumed by western medicine, but rather that Nuuchahnulth healing traditions and approaches to wellness persisted alongside, in some cases secretly, and in others in collaboration, with biomedicine. This historical account demonstrates that health services in Canada evolved over the years through a structure of racially segregated access, which, I argue, continues to inform how services and resources are allocated to reserve communities today.

“They are still trying to push us off our land”

In the case of remote Indigenous communities, institutional care is governed via a logic of exclusion which is perpetuated through the silencing of experiences of health inequity and the normalization of bureaucratic indifference. To return to the context of Nuuchahnulth *ha'hoolthi* (traditional territories) and villages, there are several case examples that reveal how social and health policy actively reconstructs the conditions for health inequity and produces a logic of care with the affective register of abandonment through geographic and social exclusion from public services. As previously mentioned, the regional health authority organizes care according to designations such as “very rural

remote” or “isolated island.” Such classifications can be a useful tool in assisting decision-makers in allocating services, focusing interventions, and providing incentives to retain health care workers in areas that are difficult to staff. However, the introduction of the idea of “remote” is also a colonial imposition that displaces notions of Indigenous self-sufficiency and political autonomy. In many cases, the designation of “remote” is often taken for granted as a reason why access to basic services such as primary care is less available. Certainly, it cannot be disputed that travel to and from remote locations is challenging. However, “remote” is also a relational term that designates a place as peripheral to the “centre.”

An eye-opening moment for me was during a public presentation hosted by the Nuuchah-nulth Tribal Council Health Department which brought together community representations from the remote Nuuchah-nulth Nations to discuss enhancing nursing services “in the Nuuchah-nulth way”. During the opening discussions, Cliff Atleo, a respected Ahousaht Elder, lead negotiator for fishing rights, and former NTC President, shared his thoughts on the idea of “remote” – which have shaped my thoughts throughout this chapter. Cliff stated that:

In Ahousaht, we don’t see ourselves as remote. We grew up here. Everything is here. It is just the services that don’t link up with *us* (field notes, May 30, 2018).

I have heard Cliff speak publicly on a number of occasions about traditional Nuuchah-nulth governance models, healing as “nation-rebuilding,” and the importance of self-determination not just for Nuuchah-nulth Nations themselves, but also through offering visionary leadership and wisdom from which the broader Canadian public would benefit. Reflecting on the idea of “remoteness” in this vision for self-determination, Nuuchah-

nulth Nations remain central, as they have since long before colonization. From my understanding, the implication is not just that services should be extended across dispersed communities, but also designed in a way that honours and embodies Nuu-chah-nulth values and approaches to wellness. I understand this vision to be a guiding principle within the NTC and one that largely informs the Nuu-chah-nulth nursing services. With “remote” villages placed as the centre of a self-determined geography of health governance, difficult travel no longer stands up as a reasonable justification for exclusion from health services. The following case studies demonstrate how the category of “remote” structures health care in a way that replicates the history of racially segregated care and normalizes bureaucratic indifference towards “remote” and “isolated” Indigenous villages.

The Relocation of Mowachaht and Muchalaht First Nations

Tsaxana is a small Nuu-chah-nulth village located along the Gold River on northern Vancouver Island, which empties into the Muchalaht Inlet. Approximately four kilometers away is the town of Gold River, which (at the time of writing) hosts a health clinic, a gas station, and a pharmacy. For groceries, one must travel an hour down the highway. I attended several weekly Elders lunches in the village, as an opportunity to share about my research and learn from the Elders. During one of these lunches, people in attendance spoke about the “fish doctor” at the Gold River health clinic; “there was this doctor who was always telling me, ‘just eat more fish, it will help’” (field notes, August 13, 2018). Several in attendance, who were all familiar with this doctor, chuckled. “I told him, ‘I can’t eat my fish no more because the fish are contaminated!’”

The people of Mowachaht/Muchalaht First Nation trace their histories to Yuquot, a longstanding village site on the southern tip of Nookta Island, where the Tahsis Inlet and Muchalat Inlet meet the Pacific Ocean. The site is rich with a sense of history and spiritual connection that continues to be important for many people. It is also a site with a long history of colonization, as visited by Captain Cook during his voyage of 1778. However, in the 1960s, due to numerous pressures, the majority of families left Yuquot to live on the reserve located near the Gold River Marina. In the 1990s the community was again moved to its present location at Tsaxana. Six years later, a settlement was reached with the federal and provincial governments due to ill health effects from contamination from a pulp and paper mill adjacent to the previous reserve location.

Reflections from the group suggested that “the fish were no good”; “we couldn’t hang laundry outside, it would get all sticky”; “everyone was getting sick” (field notes, August 13, 2018). As was described by the group, the move was challenging. The community was used to living by the sea, so adapting to life inland was challenging; as one Elder said, “I’m still not used to it.” Many of the Elders discussed the situation with bitter resentment. Since the community is still dealing with health issues believed to be connected with the pollution, the settlement has not provided any sense of resolution. A former councilor stated: “We signed the agreement, but we are still dealing with cancer, lupus, respiratory illnesses, and allergies. Is it too late? Can we still go back and say, ‘hey, we still have this cancer?’”

Figure 6: Gold River Harbour, July 20, 2019

The story of the relocation to Tsaxana raises several pertinent themes: dispossession from land, environmental discrimination, and the health effects linked to settler colonialism. However, this story and conversation with the Elders of Tsaxana was followed by a resounding concern of being ignored by service providers – including those provided by the Nuuchahnulth Tribal Council. Thus, in settler colonialism, dispossession from land and disrupted lifeways is experienced simultaneously with the experience of injustice or abandonment by public services. What this case reveals is access to health care as a form of systemic inequity, which also reveals the necessity of Indigenous self-determination over health care delivery. It is my understanding that despite the uniqueness of each Nuuchahnulth nation in terms of territory, history, and traditions, there is a commonly held experience of displacement from territories, resulting in economic dispossession and embedded in forms of political and social marginalization.

Reflecting on the history of Ahousaht, a large community located on a peninsula of Flores Island, C`aʔak, an NTC nurse, connects dispossession from territory as linked to health.

C`aʔak: There is an unbelievable amount of wealth in this part of the country, in natural resources. Unbelievable wealth. And it kind of got stripped away, kind of. It's kind of gone. Even the sense of seafood. You know they talk about food safety and let's just go back to traditional food. Well, you can't just get a spring salmon in the spring anymore. They are not necessarily there to catch, and you can't go and...

Megan: I was reading stuff in the news; people are worried about herring roe now.

C`aʔak: Oh, absolutely. So, you can't, sea urchin or digging clams any time. Both abundance and access are gone. So, this conversation about traditional food, I am kind of going, "what traditional food?" Even deer. Like they are not, we have kind of destroyed the environment in that way. So, they kind of traded off their land and all that wealth and abundance for healthcare, housing, and education. And so, look at their houses and the steps that aren't fixed. And they've got a doctor that doesn't always come up, or nurses that aren't always here. And how hard it is sometimes to get a boat to the hospital? And then look at the education, like there's just this myth that everyone goes to university for free. And that the wealth is gone forever and so there is all these government cutbacks, and they are going "really? *Really?* Really!" So, it's just a, it's a fascinating, the inequity of it that is still so glaring (interview, March 1, 2018).

Like many of those I spoke with, C`aʔak calls into question the normalization of government cuts to health spending and the inadequate availability of health care providers in Ahousaht. Yet, the *ha`wiih* of Ahousaht had never acquiesced their territory or forms of government. Rather, they continually negotiate with provincial and federal governments over key concerns such as fisheries, access to territory, education, and health care. As such, the right to adequate primary care is not simply substantiated through an appeal to overarching human rights, but rather as a stake in a historical process of negotiations in deciding how to rectify the relationship between Nuuchahnulth nations and the Canadian state. It is often framed as one of the many bargains the

Canadian state failed to uphold. In such light, health inequities appear not just as “avoidable” by-products of inadequate policymaking, but more so as a deliberate failure. In concealing the fault of the Canadian government to provide what was promised, the notion of “remoteness” offers an easy way to explain disparities in access to primary care as inevitable rather than avoidable.

The Kyuquot Health Clinic

Houpsitas Reserve, also referred to as Kyuquot, the setting which opened this chapter, is home to a community of approximately 160 members of the Ka:’yu:’k’t’h’/Che:k’tles7et’h’ First Nation, on northern Vancouver Island. Across the Kyuquot Sound is a strand of islands dotted with fishing resorts and a few sparse homes. Until 2017, the reserve population was required to travel by boat to Okima Island where the Island Health nursing station was located (a former pay-for-service Red Cross outpost). For many years, Nuuchahnulth health leadership were frustrated that health services were situated on an island that was more readily accessible for the largely non-Indigenous fishing tourists, but across the bay from where most of the permanent population in the area lived. In October 2017, the Ka:’yu:’k’t’h’/Che:k’tles7et’h’ First Nation opened the doors to the brand new Kyuquot Health Centre. As a result, the outpost nurse would now work from the health centre, in the heart of the community, four days of the week, and locum doctors would arrange their appointments from the Kyuquot health clinic rather than the Okima Island outpost. The opening of the new centre brought the outpost nurse into the community, greatly increasing the number of community members seen by a health care provider as well as follow-up appointments to manage ongoing health concerns (Plummer, 2018).

However, this was a hard-won success by the nation. Prior to the Kyuquot Health Centre, there was a health clinic in the community that had remained empty due to disrepair. The nation had negotiated an agreement with Health Canada to renovate the clinic. In 2011 Ka:'yu:'k't'h'/Che:k'tles7et'h' First Nation signed onto the Maa-nulth treaty, signifying a significant increase in self-determination, however it also provided cause for Health Canada to stymie funding for infrastructure improvements. As was relayed to me by members of the nation's leadership, the nation instead worked with private investors to build the clinic. Once the clinic was completed, more consulting was required to negotiate with the regional health authority to move health care providers onto an on-reserve clinic. As one councilor for the nation stated, "so we had this beautiful facility that for a while it wasn't being utilized" (interview, March 15, 2018).

On a sunny day in March 2018 in Kyuquot, I was eating my lunch on a bench outside the health clinic when the occupational therapist (who had flown in from Port Alice, BC), the Island Health outpost nurse, and an NTC Home Care Nurse approached. I overheard them talking about how "crazy" the occupational therapist's (OT) schedule was, having to travel all over the north island and coastal area. The OT noticed me and suggested I come with her and the NTC nurse on their home visits. The first house belonged to Kałhak, an Elder who lived with her granddaughter and her young family. Cartoons were blaring on a large TV in the living room. A young woman was rocking a baby while another woman was in the kitchen making sandwiches for the family. Kałhak sat on a rocking chair in the back corner of the living room. I said hello to her granddaughter, ʕupak, whom I had met the previous day. ʕupak had been acting as the primary care giver for her grandmother. As soon as the OT was in the door, she got

straight to work, asking “what do you need?” The OT suggested a tub rail, chair cushion, and a new wheelchair. The OT inspected Kałhak’s injuries related to a recent broken hip. She cut a few strips of physio tape to stabilize the hip (“my magic tape!”) and also applied some for Ħupak’s sprained wrist. I thought this was an insightful thing to do, as the previous day Ħupak had discussed the challenges of caring for both her infant son and her grandmother, while suddenly developing wrist pain that only added to her stress. The OT had remarked it was likely due to a strain from over-use.

There was some discussion around follow-up care for the family, and then quite suddenly we were walking on to the next house, where Tiihuup lived. He lived in a newer home, which now had some dirty dishes, garbage, and dog feces strewn around in it – I presume a consequence of his recent health troubles. The OT looked in his bedroom and suggested a few things he was agreeable with: a new shower head, tub rail and chair. I had also spent some time visiting with Tiihuup that week and understood that he had collapsed from cardiac arrest a few weeks ago. Since the episode, he complained that he has been feeling weak and prone to falls. The NTC nurse who had attended the incident expressed to me that she couldn’t believe how fast he had recovered. Towards the end of the visit, the health care providers asked if there was anything else that he needed. “Just a wife” he stated with a sly laugh.

After visiting a few more homes, we returned to the health clinic. A man who had been waiting there informed the occupational therapist that he had been waiting for an appointment for six months. He was disappointed that he had followed up with the NTC nurses but never heard back. The OT sympathized: “that’s my fault. I haven’t been out here.” Just before entering the clinic, we had been having a conversation about how she

wishes she could visit Kyuquot more often or be able to offer consistent follow-ups for existing clients, but Island Health will rarely fund her travel. She explained: “It is a huge ordeal to apply for it [travel funds] and then it’s often not approved. It has to go to the CEO in Victoria. It’s surprising the things they won’t pay for!” As a result, the day presented a unique opportunity for her to work in collaboration with the NTC home care nurse, to ensure they can work together to support clients. The day occasioned an important opportunity for Kałhak’s recovery from a broken hip by approving her for a fitted wheelchair and cushion. However, she would need continued assistance with re-inflating her cushion and checking the incision wounds on her hip. Therefore, collaboration is crucial, not only by making occupational therapy available in Kyuquot (occupational therapy is only approved for travel if there are other healthcare professionals travelling as well and at least four patients requiring the service) but also in ensuring the clients have continuity in care to ensure a full recovery after major surgeries or health events.

Responses from NTC nurses, however, indicated that these moments of collaboration between NTC nursing and Island Health services are rare. For instance, Łay’ama Nuči shared her frustration with an ongoing struggle to access the professional support and equipment needed to help her clients in Tsaxana, Ehattesaht and Kyuquot to continue to live safely at home in remote communities:

When you’re in a community that’s rural and remote, trying to find the right service – ‘cause you get turned down all the time – trying to find any services outside of you, it can be so frustrating! . . . As a nurse, well as a patient too, to find a service is so frustrating and time consuming that you’ll literally give up . . . Like occupational therapy, trying to figure out who to help you with getting a wheelchair. Just getting stuff that fits! And having somebody [professional] who fits it. Because I don’t know how many people, I’ve seen walking around with the

wrong height of a cane or walking around with the wrong height walker. And then they wonder why they fall over? (interview, March 27, 2018).

Ɔay’ama Nuči’s account reflects the frustration and grief that accompanies health inequity in access to health services. As was shared, navigating limited access and resources in remote communities often requires choosing between continuing to fight an unending battle or choosing to give up. Both scenarios require living at risk, where the other alternative is to leave the community altogether. This is a choice many Nu-u-chah-nulth families make, especially as a means of ensuring their elderly loved ones who may be at risk of having a fall or health complication due to chronic illness or recent injury are well cared for. This is not an easy choice for families to make, as it is experienced as a disruption to cultural knowledge and community cohesion with myriad effects for both families, communities, and individuals who may choose or be persuaded to leave. As Ɔay’ama Nuči reflected:

Because we don’t have these services we either lose a family, they have to leave, and they lose all their support system and all their visitors because they live in Kyuquot. Or how do we get them to stay home? How do we do this? And we have to be risk takers, and they have to be risk accepters (interview, March 27, 2018).

By “risk accepters,” Ɔay’ama Nuči is referring to the choice to stay in the community, knowing that access to specialists, medical equipment, and urgent care is considerably more limited for those living in “remote” villages. Hasp’iqak, a leader from Kyuquot powerfully remarked that with the limited services available in remote communities, combined with the high costs of travel, food, and necessities, “it’s like they are still trying to push us off our land” (interview, March 15, 2018).

Conclusion

Returning to the idea of “remoteness” as an explanation of lack of access to health services, what happens when the centres of Nuu-chah-nulth commerce, trade and governance come to be defined in this way? In the context of health services, the term implies that travel to and from the community is long, arduous, and often unreliable. By applying a term with such connotations as an “objective” descriptor of the reality that travel to and from that place is difficult, this normalizes a bureaucratic indifference that access to health services cannot be improved because it is simply a matter of a “very remote and rural” place. Whether or not travel should be made easier (and therefore also more publicly accessible) through the development of, for instance, pavement and guard rails along steep logging roads, is ultimately within the purview of the nations themselves and not something I intended to make any concrete recommendations about. However, these categories delineate access to health services in a manner that is both racialized and inequitable and which justifies the allocation of resources to settler communities above others. I also have outlined some of the connections between barriers in access to primary care in remote communities as they are today and historical processes such as racially segregated health services as a means of improving the vitality of the settler body politic at the expense of the colonized.

The idea that “they are still trying to push us off our land” haunts my thoughts concerning the stories shared with me about struggles to obtain care in remote communities. Several Indigenous scholars have written about settler colonialism as the means and motivations informing political actions made by the Canadian state. Settler colonialism is conceived as an unfinished product, through the ongoing acquisition of

territory (Simpson, 2014). While the means of acquisition has taken diverse historical forms – whether direct violence, assimilatory policies, or liberal politics of recognition – the imperative to possess land and resources for economic development continues to take precedence over Indigenous claims to territory, governance, or equitable distribution of services (Wolfe, 2006). The connection between settler colonialism and bureaucratic indifference expressed through the lack of access to primary care reflects the centuries-old historical memory of displacement from land and unmet promises.

Not all the narratives shared with me regarding illness and care in remote communities carried an affect of abandonment. Several stories shared described a strong sense of collaboration between NTC nurses and physicians who ensured the needs and safety of terminally ill family members were met. Supportive and culturally safe care can and often is made available in remote communities. However, what I hope to have highlighted by centering my discussion on experiences of abandonment is a pervasive recognition, among the Nuu-chah-nulth-aht with whom I spoke, of differential access to care in comparison to the broader Canadian public. I also have elucidated the institutional structures that inform disparities in access to health care and their historical precedents, as well as how these structures reduce the opportunities available for relational care.

In closing, I revisit the idea that access to and quality of care are indistinguishable aspects of health equity from a patient perspective; both are experienced as forms of discrimination. In speaking about this research in spaces outside of the field, I have noticed a tendency to categorically distinguish between the stories that were shared to me as either irrefutably an instance of discrimination, or an unfortunate side effect of living in a remote location, or of a poorly organized health care system. However, I would argue

the distinction is artificial. It is in speaking to these conversations that I address the question of access in unpacking anti-Indigenous discrimination in the public health system. I realize that by focusing specifically here on access, I am contributing some substance to the distinction between quality of care – where patients are treated with dignity (or if not, then there is a gross neglect of humanity wherein someone must be made accountable), and the question of access – whether a system is sophisticated and well-funded enough that health risks and needs are “adequately” attended to (or if they are not, then this is an unfortunate consequence of oversight). Yet, my intervention is that both must be understood as manifestations of targeted discrimination because both dimensions of health equity are experienced by patients as targeted discrimination. Moreover, neither criteria can be disentangled from the colonial history of health care in Canada.

As I will address in the following chapter, there are forms of personal and historical trauma that are difficult to de-link from lived experiences of structural violence, such as that experienced by residential school survivors or former Indian Hospital patients. I believe that a health system that fails you cannot be experientially disentangled from all the other institutions that either neglect or deliberately oppress you. Conversely, when taking the perspective of substantive equity, a poorly organized health system with limited primary care is not an acceptable way of managing health services targeted to a population experiencing demonstrated health disparities. I believe this contributes to the tendency, when speaking about stories of culturally safe or unsafe health services with Nuuchah-nulth-aht, that a story of blatantly racist remarks given by a doctor may be followed by another narrative about a particularly long wait time in an emergency

department. Ultimately, if both these types of narratives are shared in the same conversation about “culturally safe care” then they most certainly need to be taken up by those listening – especially those in positions to make health system decisions – as congruent dimensions of cultural safety for Indigenous patients. A dichotomy between quality (respectful, dignified care) and access (an impartially imperfect health system) does not reflect what the issues objectively are; rather it shows how those listening construct the issues. My intended contribution is to open dialogue along the lines of what happens when weaknesses within the health system are understood as targeted forms of discrimination. My thought is that the public and decision-makers may then begin to understand the connection between existing infrastructure, historical socio-economic marginalization tied to colonialism, and explicit instances of discrimination. There is a need to reframe access to care as encompassing both inequities of place (accessibility, infrastructure) and inequities of race as underlying structures of settler colonialism.

Chapter 5: Racism and the Socio-Affective Constitution of Health Care Experiences

Figure 7: Wild foxglove along Cherry Creek Road, Port Alberni, June 11, 2018

While capturing the above photograph, I was contemplating the question: poison or medicine? Based on my understanding of folk herbal medicine, the foxglove, *Digitalis purpurea*, is fatally poisonous for human consumption. But this plant can also be used as an effective treatment in cases of cardiac arrest. This dual ability to both heal and harm applies to other herbal medicines as well. For instance, devil's club, or *Oplopanax horridus*, is a spiritually powerful and commonly used medicine on the west coast. However, the spines covering the plant are problematic for harvesters and the fruit it

produces is toxic to humans. In both cases there is a depth of knowledge required to know when to harvest the plant and what parts can be used to prepare medicines. This curiosity of herbs, of powerful medicines as being also quite dangerous, I find is reminiscent of Atleo's writing on *chih-shitl*, a process of communication with supernatural beings, that often results in the acquisition of powers that can be used for purposes such as healing or the ability to capture a whale for food. *Chih-shitl* is roughly translated as "fearful experience" as an indication of the ever-present dangers in both physical and spiritual dimensions of reality (Atleo, 2004). My own take on this is that power can be used in terrible ways, and the ability to induce healing can certainly be considered as a source of power – whether the spiritual power embodied by *ʔuštaqyuu* (medicine man), the profound effects of pharmaceuticals on the human body, or the authority socially ascribed to medical doctors. This chapter explores care and healing as imbued with power with the potential to both heal and harm. Specifically, this chapter explores instances where biomedical care produces harm at the same time as it promotes healing or fails to effect healing at all.

In the previous chapter, I demonstrated how infrastructure and access to health services should be considered as a dimension of health equity and that facing barriers to accessing care is often experienced as a violent form of discrimination. Not being able to access care and being directly refused care based on a racialized assumption on the part of a health care provider are both experienced on a similar affective register of social abandonment, which can be sharply contrasted with more relational modes of care. In this chapter, I look more closely at the quality of care as a dimension of health equity and how discrimination factors into and constitutes health care experiences. I pose the

question of how past experiences of discrimination shape perceptions of health care or accessing health services. Additionally, I examine how anti-Indigenous racism continues to operate within health services at a systemic level, and the lived effects of this. I consider exclusionary and relational as two affective registers of care. As such, I extend this exploration by looking at how experiences of discrimination constitute health care experiences and the normalization of discriminatory attitudes and practices in health care.

Systemic racism within health services has been a site of increasing attention in recent years (Allan & Smylie, 2015; Browne et al., 2011; Tang & Browne, 2008).³⁵ I understand “race” as a socially constructed category of otherness based on perceived biological difference and cultural or behavioral inferiority that, through racism, engenders exclusion, marginalization, and economic and political inequity (Farmer, 1997; Johnson et al., 2004; Wolfe, 2006). In this chapter I examine racism in health care through a focus on processes of othering that rest on perceived difference to produce implicit bias on the part of health care providers about Indigenous patients that further engenders biomedicine as an exclusionary mode of care. To do so, I track between the interpersonal manifestations of racism and the systemic processes that feed into and perpetuate exclusionary practices in health care³⁶.

³⁵ For example, at the time of writing there is an independent investigation initiated by the BC Minister of Health to address allegations of anti-Indigenous discrimination in emergency departments across the province.

³⁶ Some scholars writing on this have argued that class or socio-economic status is more indicative of health disparities than racial categories (Krieger, 2000). I am in alignment with Farmer (1997) that it is necessary to examine the intersections between race and class as health disparities are tied to social inequity which can manifest both as racial exclusion and income disparity. However, in the context of my own work I look specifically at the health care experiences of Nuuchahnulth as a historically racialized group.

Systemic racism is racism that is embedded in the fabric of society, including the attitudes and approaches taken in formal institutions such as law, education, and healthcare. Opposed to overt interpersonal racism, systemic racism is subtle (Carmichael & Hamilton, 1967). Systemic or structural racism are self-perpetuating spectres, as “they are constantly reconstituting the conditions necessary to ensure their perpetuation. Even if interpersonal discrimination were completely eliminated, racial inequities would likely remain unchanged” (Gee & Ford, 2011, p. 115). In other words, overt racism is experienced interpersonally but is sustained systemically as a facet of society and as it continues to act on individual experiences of healing and care. Systemic racism is embedded into metanarratives about how we treat one another including how we organize institutions and function as a society. Additionally, “systemic racism is not only enacted proactively in efforts that create racialized inequality, but also in the failure by those in power to redress such inequalities” (Allan & Smylie, 2015, p. 5).

Since its inauguration, the First Nations Health Authority has been quite vocal about acknowledging ongoing anti-Indigenous racism within health care settings (First Nations Health Authority, 2015). The FNHA also acknowledges cultural safety as an approach to improve the quality of health care, which in turn increases access to care for First Nations peoples. In a recent regional health survey, it was found that 28% of adults in the Vancouver Island region reported personally experiencing racism in the past year, although it can be assumed that many of these experiences remain unreported (First Nations Health Authority, 2019). Leadership and front-line staff at the NTC are acutely aware of the fact that experiences of discrimination while accessing health services pose an immense barrier to care for Nuuchahnulth-aht. For example, a recent investigation

revealed that 90 Nuu-chah-nulth elders living in Port Alberni were coping with untreated chronic conditions, resulting from a lack of culturally safe care.

Disturbing accounts of interpersonal racism have been shared throughout my own field research as well as through numerous recent studies conducted on the issue of anti-Indigenous racism in health care (Browne & Fiske, 2001; Browne et al., 2011; Goodman et al., 2017). Presently, resources are being allocated on all levels of health systems in the province of BC to address this troubling issue. However, interpersonal racism accounts for only the visible manifestations of the issue. Addressing the root causes, the systemic nature of racism, requires investigating the ideologies, assumptions, practices, and structures within the health care system that reproduce the inequities which trace the contours of colonial racialized otherness. Relatedly, this requires following the links between the interpersonal nature of health care encounters and the systemic dynamics that shape these encounters. Evoking processes of racialization when addressing health disparities comes with an inherent risk of further pathologizing Indigenous peoples, or perpetuating the image of Indigenous peoples as victims (Tang & Browne, 2008). Contributing to this discourse supports paternalistic interventions, and thereby undermines claims to self-determination (O'Neil et al., 1998). This is a difficult position to navigate, as I feel a responsibility to carry forward the stories that were shared to me, without displacing Indigenous voices or inadvertently perpetuating the assumptions I wish to unmask. My intention in this chapter is not to reproduce a dichotomy between oppressive doctors and oppressed patients, but rather (while still maintaining a sensitivity to power imbalances) uncover how systemic processes manifest in health care encounters, despite the best of intentions.

Health care experiences should be recognized as encompassing more than interpersonal tensions or a failure to appreciate “folk” models of health and illness, but rather as a manifestation of systemic and intersubjective influences. Building on the discussion from Chapter 4 on biomedical modes of care as exclusionary, I explore how seemingly innocuous practices can inflict harm through implicit racialized assumptions. I begin this chapter by taking account of current and historical experiences of racial exclusion in health care. I then explore how trauma (attached to personal, family, and community histories) associated with health care experiences creates affects that continue to constitute health care experiences. This leads to mistrust, avoidance of health care, and a failure of mutual understanding between patients and health care providers. This also has grave material consequences as the dismissing of patients leads to prolonged suffering and even preventable death. I then demonstrate how practices within health care constitute the stereotypes that are drawn upon as a justification for discrimination. Lastly, I argue that these limits of intersubjectivity, these failures to understand the lived experiences of patients, must be acknowledged in order to effectively implement culturally safe care.

Taking Account of Racialized Exclusion

So those things all add up in my mind. Are we really getting the full, equal treatment in the services? As First Nations we can feel that. If there's prejudice or discrimination against us. Every person is different, every nurse, every doctor. And you can feel it. They put you at the end of the line for some reason (Elder, Ahousaht First Nation, interview, February 15, 2018).

It is an incredible thing to have complete faith in strangers to do everything in their power to save your life. As such, emergency rooms and urgent care clinics engender a space of intense (and at times coercive) trust and obligation. But what are the limits to this? What

happens when the contract of trust between physicians and patients is broken?

Discrimination when accessing health services is a devastatingly common experience for many Nuu-chah-nulth-aht. The weight of the stories shared in this chapter express the pervasiveness of the issue.

To illustrate, an older gentleman from Tsaxana explained that: “I went to the doctor in Campbell River. I tried to get my prescriptions here [in Gold River] and I got scolded for asking what the doctor had prescribed me. ‘Are you a drug addict? Why do you take all that?’ ” (interview, August 13, 2018). Often, systemic racism within health care manifests through widely held stereotypes about First Nations patients. An Elder from Uchucklesaht First Nation explained that:

Last month, I was at a meeting to talk about mistreatment in hospitals. Why do I have to go to this extent to get the same treatment? . . . They lump us all together: illiterate, drunk. I can understand language really well but they don’t take the time to listen (interview, June 21, 2018).

Whenever racial stereotypes are evoked, the result is that the patient’s own account of their illness is dismissed, they are refused medication – even renewal of pre-existing prescriptions – and often sent home without thorough examination. In some cases, this has resulted in unnecessary loss of loved ones, who had been sent home from hospital or died in-hospital, without having received treatment.

In cases where a patient can treat their condition through other means, there remains an affront on their sense of dignity. Waaxni, a Yuułuʔiłʔatḥ (Ucluelet) Elder shared:

Waaxni: We had an incident; this guy was so rude to us. He was a specialist. I don’t know if he intentionally done it, but he was so rude. Like, saying that the reason my grandson is like that [suffering from psoriasis] is because we have too

many people in the house. I said, “its three of us in the house! It’s a two-story house and you are trying to tell me we are crowded.”

Megan: Yeah, they just assumed?

Waaxni: The specialist was I think Hindu. And he said “well that’s how you natives live. You are from Ahousaht³⁷ aren’t you?” And I said, “woah, no.” I said, “I am from Ucluelet.” But he was just very, I reported him to the doctor. I couldn’t deal with him because we shouldn’t have to deal with that kind of stuff (interview, April 16, 2018).

As Waaxni and others have described, racialized assumptions manifest in overt ways during health care encounters.

NTC nurses regularly support Nuu-chah-nulth-aht in forwarding complaints about experiences of discrimination. However, many participants remained skeptical that the present complaint process accomplishes much in terms of improving patient experiences.

As an experienced NTC Home Care nurse explained:

We constantly get clients complaining about their doctors, or the hospital emerg., and mistreatment, the way they are spoken to. And we are always encouraging them to, you know, write letters, or we can help them get letters written up. But it's almost a weekly event that we hear from somebody . . . Because of some of the stories of what we hear from Aboriginal clients that go to emerg. And the first thing they say to them is, “how much did you have to drink?” And a lot of them don’t even drink. Or they’ll have blood work, and their liver enzymes are out of whack, for other reasons. And yet they are saying, you have liver cirrhosis ‘cause you drink too much, and they [the doctors] don’t listen that “I don’t drink”. So right away there are criticized, they are judged. You know, they are reprimanded. And they are not listened to. And they are totally disrespected. And it triggers them right back to residential school and the treatment of the white man. We have so many clients that literally will not go to emerg. unless they are on the death bed.

Actually, I had a client last week I was really worried about. I told her she needed to go to emerg. and she wouldn't go. She would not go. And I was really worried and concerned. And I said, “ok well can we compromise?” I said, “can you go to the walk-in clinic?” And I finally convinced her to go. Well, the doctor sent her straight up to the hospital. Like she was really sick. So she would choose to lay

³⁷ Ahousaht First Nation has the largest on-reserve population of the Nuu-chah-nulth Nations. There is a commonly perception amongst non-Indigenous locals of Ahousaht as a place of drug dealing and crime.

in bed for weeks. And not eat, not drink, dehydrated. And feel like she's losing the battle before she's going to call the ambulance or go to emerg. *That's how bad it is* (interview, December 7, 2017).

This nurse's experiences point to a failure of the contract of trust between patients and the health care system. With awareness that the health care system is liable to fail Indigenous patients on the basis of persistent racist assumptions, hospitals and urgent care clinics – instead of being a site of relief – become spaces of abandonment and social suffering. NTC nurses find themselves in the tenuous role of extending biomedical health services to alleviate suffering and improve health in Nuu-chah-nulth communities, while the health care system they seek to extend repeatedly fails Indigenous patients. In this context, a relational approach to care is necessary to remedy the trauma associated with health care experiences.

As demonstrated through the above stories, discrimination and anti-Indigenous racism are often experienced through explicit comments or actions of health care providers. However, discrimination is also experienced at a more subtle, systemic level, observed through unnecessary barriers to care. For example, an Elder couple living in Port Alberni, Cix^watin and ʔaama, described the ongoing struggle to find long term care for a relative who was struggling with substance use as well as chronic illness:

And you know all the services for elderly or senior citizens in the city are hard for the Aboriginal peoples. There are services, but they aren't culturally sensitive to our peoples. And I've told this to NTC, the head of the NTC nurses. 'Cause we had to help a couple seniors get into the home. . . Rainbow Gardens. It took a couple years. In and out of the hospital. The hospital kept letting her go. Not until later someone told them why they do that, so they don't have to follow through with putting them in a home. That's what we found out. So we told the nurses. She said you guys keep bringing her, we are trying to work on getting her into a home. "Well why doesn't her family look after her?" We're in this, we are the young ones of the family! She was the youngest of the family. Everyone else are senior citizens. Some are older than her! Expected to help her, and all her kids, it just so

happened that all her kids were gone eh. Died from alcoholism and stuff like that. You know she had a sad life. And we had to tell the nurses that, all her life history. You know, knowing the person, she's not just pretending! She's not just pretending (interview, February 15, 2018).

While it remains unclear why exactly this individual was denied access to long term care from a health system or provider perspective, this story illustrates how people experience such encounters and barriers to care as examples of discrimination in health care, in the context of their wider experience of historical, systemic, and interpersonal racism. In advocating for better care for their loved one, this family had to repeatedly testify to their family history in order to justify the need for access to services. Stories such as this identify the pressing need to enhance culturally safe care through *both* increasing access to primary and emergent care, as well as reducing anti-Indigenous discriminatory procedures and behaviors within the health care system.

Affective Constitution of Health Care Experiences

Cix^watin and ʔaama, an older couple with a sharp sense of humour currently living in Port Alberni, described how feeling disregarded by health care providers permeates their experiences dealing with the various health concerns that have arisen over the past few years. The following is but one example of the numerous anecdotes they shared that illustrated to them that First Nations peoples are “treated unfairly” when it comes to health services.

ʔaama: I recently had this surgery and they found a growth on my bladder. And it got removed, and I got sent away. And the day after I got home, they put on a – what do they call those things – where I have to walk around with a bag. They put one of those on me and the next day after I got home I thought it was leaking. So I called the doctor's office that did the surgery. And she [the receptionist] said, “oh we can't fix that here, you need to go to emergency, they will fix it for you there.” I said “but the lineup is usually three, four hours. I have stitches. I can't sit there for that length of time.” “Oh, you just had surgery. They shouldn't be doing that. They

won't do it." I ended up walking out because that's exactly what they did. I waited for three hours, I couldn't stand it anymore and I walked out.

Megan: So you didn't get looked at?

?aama: No.

Ćix^watin: Just because you are not dying or bleeding to death. That little thing is an emergency to some people! It would take two minutes to fix it. It's a matter of plugging it back in. I would do it for her, but she wouldn't let me. You got to wash your hands after! [laughing] So that's the thing we wonder. Are we being treated fairly here? (interview, February 15, 2018).

Although this frustrating experience could have potentially happened to anyone, the story takes on new meaning when understood in the context of this couple's personal history.

Ćix^watin and ?aama met in the Alberni Indian Residential School, and despite being separated and disciplined for their association, maintained their companionship.

Ćix^watin: But I made a lot of friends there [in residential school]! I protected myself by having friends. I broke the rules and I got kicked out. I didn't go to church. I didn't like to do the things they were forcing us to do. I went there for school! I would go to school and stuff like that. I mean that's where we met! We got a letter written by the principle to her parents. "We are concerned with your daughter, she's with a bad guy you know." [laughing] We look at it once in a while.

Megan: You still have it?

Ćix^watin: Oh yeah [laughs].

Megan: That's a cute story actually.

?aama: That guy is still alive too.

Ćix^watin: Yeah, that guy used to say, "Wally, her parents will never let her marry you!" "Oh, that doesn't matter to me," I said. We wanted to invite him to our 25th wedding anniversary (interview, February 15, 2018).

After choosing to stay permanently in Port Alberni, they found that "off-reserve" status meant that they were no longer eligible for the services, programs, and medical funding which their home communities provided to members, due to colonial policy linked to the

Indian Act. Understood in the context of facing exclusion from services on more than one front, an unnecessary wait for a minor issue resulting from a recent surgery reflects a lifetime of previous experiences of being removed and excluded, during their residential school experience, on the basis of not conforming to imposed colonial criteria of belonging and deservingness. Such experiences are often rationalized by health care providers as being subject to standard procedure. However, in the course of one's lived experience, these events are placed within experiential knowledge. In the context of health services in Indigenous communities, care expectations differ not only because of cultural beliefs surrounding health, but because certain aspects of the health care system are unbearable for those who have survived abuse, racism, and historical trauma. Past experiences of discrimination and trauma – whether personal, familial, or part of community histories – associated with health care experiences create affects that continue to constitute health care experiences.

Lingering Affects

Trauma has become a ubiquitous term in conversations around colonial policy and cultural safety in health care in North America. The term itself carries multiple connotations. There is an extensive literature exploring trauma as an aspect of colonial subjectivity (Fanon, 1963). In a clinical sense, trauma describes acute injury or suffering, or indicates a psychopathology (i.e., post-traumatic stress disorder). Additionally, the concept has been expanded to express Indigenous experiences, through concepts including historical trauma, cultural trauma, or intergenerational trauma. This extension of the use of trauma has been adopted in the language of international human rights, identifying the cost of social upheaval resulting from war, oppression, forced

displacement, or poverty. In speaking to the effects of colonialism, trauma provides the “explanation and site for action, capable of making sense of the multiple social, psychological, and material outcomes of colonialism” (Million, 2013, p. 100). Through this formulation, historical trauma has been articulated by Indigenous scholars to express the enduring, intergenerational nature of colonial trauma³⁸. Trauma carries social and political power, in the sense that it affords a language that “enables people to express the relationship between the past and its structurally oppressive forces, and the link to contemporary realities” (Czyzewski, 2011). Moving between these multiple readings of trauma, I apply the term here not to pathologize these experiences, or to identify the inner turmoil of “colonial subjectivities.” Instead, my focus is to draw on the notion of historical trauma, or lingering affect, to outline the connections between past experiences of racism and discrimination and recent health care encounters.

An Elder from Mowachaht/Muchalaht First Nation explained that there are “a lot of health issues from the residential schools. That is still trickling down through the generations” (interview, August 13, 2018). My interpretation of this comment is that these health issues are likely both physiological and psychological. The residential school system removed children from their families and the guidance of elders to instill in them compliance to Eurocentric notions of healthy practices (Kelm 1998, 63). Residential schools were systematized from 1850-1996 through a partnership between the

³⁸ However, the dominant understanding of trauma continues to be largely shaped by the DSM-III and the institution of psychiatry. Evoking narratives of trauma can be both empowering and subjectivizing as narratives are placed within the frameworks of social programs that entail “self-examination, psychological evaluation, and testimony for legal domains of victimization” (Million, 2013, p. 94). Trauma can provide empowering narratives in the sense that writers and activities have taken it up to mobilize “affective testimony” (Million, 2013, p. 94).

Presbyterian (in Ahousaht and Port Alberni) and Roman Catholic churches (in Clayoquot) and the Federal Government. Residential schools were paradoxical in that they taught that healthiness could only be obtained by disregarding one's cultural upbringing, yet the schools exposed children to disease, abuse, malnutrition and overwork (Kelm, 1998, p. 59). The residential school system was supported by the ideology that Aboriginal families were incapable of child rearing, through which missionaries actively reinforced a division between Indigenous tradition and health.

As discussed in chapter 4, Indian hospitals imposed racially segregated care. The residential school system and Indian hospitals were systematically linked; Indigenous children and youth were often transferred between one institution and the other, sometimes without even informing their parents. Both institutions worked to undermine Indigenous family structures by removing young people from their communities for extended periods of time. Both institutions imposed strict behavioral and social regimens (Meijer Drees, 2013). A concerning effect was that these institutions offered sub-par standards of care and consent. Furthermore, the Indigenous population admitted to Indian Hospitals were at times used for experimental drugs and treatments (Meijer Drees, 2013, p. 10). The strict routines and discipline enforced within Indian hospitals produced a feeling of oppression reported by many former patients: "patients felt not only the physical pain and discomfort of a terrible disease, but they were also subjected to forced confinement, foreign environments, separation from community and family, confusing and sometimes bewildering Western medicine – all compounded by cultural and linguistic isolation" (Meijer Drees, 2013, p. 60).

While visiting the seaside community of Hitacu, I met with an older gentleman, Čims, who shared a story about his experiences in the Nanaimo Indian Hospital. Čims was placed in the Nanaimo Indian Hospital as a child for tuberculosis treatment, from the ages of 7-10. He described that he was forced to take medication, without understanding why, and witnessed other children becoming ill after being administered a strange liquid. He described being locked in a pitch-dark room for extended periods, being forced to eat bad food, and then forced to eat vomited food, as well as having food withheld from him. Due to these experiences, Čims described feeling a sort of numbness to pain for years afterward. This led him to “fall into crime” and was in prison for much of his adult life. Later in life, he returned to his community and worked hard to reintegrate back into “outside life.” He remains skeptical of the early diagnosis of TB and suspicious of the treatments he was subjected to. Čims spoke to me with a wish to find justice and understanding for the experiences he had as a child in the Nanaimo Indian Hospital.

Through the combination of residential schools and Indian hospitals, many Indigenous children were subjected to confusing and terrifying experiences. Qaqup, a Nuu-chah-nulth elder, shared that both her and her mother had been subjected to segregated health institutions as children.

Qaqup: I'm not sure where to begin, because I've had health issues from the day I was born, because my dad told me I was in the hospital with TB. For how long, I don't know. And, because I guess, what I am noticing is, there is a lot of change in our health system. I am thinking for the better. But there are a lot of things that are needed to be changed.

Megan: You have some examples of things that are getting better?

Qaqup: I really think the interaction with health care people, people in health care, whereas before, I really don't want to say it's being racial, like there were only certain doctors that we were allowed to see.

Megan: How long ago was it like that?

Qaaup: I can remember from age eight and up. Being here at the residential school. Because there are different, different areas of like where you get your glasses, or you get your teeth looked after. Not knowing, like my mom told me her teeth got pulled when she, I'm not sure when that was, that her teeth started to come out, but when they start, they took out all the teeth (interview, June 13, 2018).

In a composed, matter-of-fact manner, Qaaup continued to describe her own issues with dentists. Qaaup joked about her own tendency to avoid visiting the dentist, yet the story of her mother having her teeth pulled as a teen affected me as being quite horrific. However, the removal of body parts following a questionable consent process is a shockingly common occurrence.

I find that textualizing accounts of trauma is a difficult task. Interview transcripts and notes contain a record of the content of speech during the sharing of these stories. This should seem like an obvious starting point but to connect abstracted speech forms with the living presence of these words in the lives of those who spoke them is not a straightforward task. The stories tended to flow through the normal course of conversation, yet their gravity hung heavy in the air and in my chest as I listened. I do not know what to make of them, other than to carry them forward so that they may continue their work of unearthing the silent memories and affects that continue to shape the form of health care encounters.

In my basement apartment, K̓ayuumin, a spiritual healer, shared her experiences working covertly as a healer in the local hospital. She also talked of her efforts to encourage others to advocate for themselves in health care:

So, we're not putting ourselves in a position of somebody that thinks [they have] authority over us. Nobody knows your body, but you. That's what I always say to

people. I said, nobody knows more than you. It's just so many traumas in the past. We put them [doctors] under authority right away. And I learned that from my mom. My mom was in an Indian Hospital for two years. They took out her one lung and she didn't even have to; she was only a child. She was in there for two years and didn't even tell her parents, her dad; her mom passed away. But then her dad was so mad he didn't even know they took her lung out. So I learned from then to speak up, ask questions. That's all it is. Ask questions. What's your name? And I always encourage people and try to teach them, have a piece of paper and write down their name right away. And then so they see you, the nurse sees you, the doctor sees you, a lawyer sees you. Anybody that mistreats you or makes you feel uncomfortable that you're serious about their services (interview, May 21, 2019).

For readers like myself with no direct connection to Indian Hospitals, perhaps we can imagine for a moment our own children having a lung removed without having been informed, without being able to be there to support them through the procedure. If you can feel the gravity of that experience, then you may also sense that this gravity is not something that easily dissipates. Many families have made peace with this trauma, but what efforts have been made to reconcile this broken contract of trust between health care providers and patients? This broken contract is the gravity which in itself can lead care to cause harm. This is not a solitary account. Historical research has shown that lobectomies were a common procedure in Indian hospitals, often without patients' or their guardians' full consent. Along with this, has been long-standing suspicion within Indigenous communities that people were admitted to the hospital who weren't sick as a means for these institutions to gain additional funding or subjects for experimentation (Meijer Drees, 2013, p. 202). These family histories are carried forward through recent experiences of discrimination while accessing health care services.

Ongoing instances of racial discrimination in health care settings – coupled with lived and intergenerational trauma associated with residential schools, Indian hospitals, and other forms of state-mandated assimilation and oppression – implies that health care

experiences are a potential trigger of trauma for many individuals. Našuk, an Elder from Uchucklesaht explained that, “anyone over 50 has been to residential school. When you are in the hospital, sleeping feels like the institution where we grew up. When you wake up with the nurse standing over you, you think it is the offender who raped you” (interview, June 21, 2018). The gravity calls forth repressed memories and affects, making dark personal and social histories live again in the present moment.

Over a cup of tea at the kitchen table of her daughter’s home in ‘Port Side’ Port Alberni, Našuk recounted troubling stories indicating the present form of anti-Indigenous racism in health care services. When her stepbrother suffered a bleeding head injury, she accompanied him to the local hospital. He joked, “I fell down and I wasn’t even drunk!” Našuk suggested he shouldn’t speak like that. He waited hours for care with profuse bleeding, which she felt should have been triaged for immediate care. “I am still upset about it,” Našuk said. She herself had a similar experience at the same hospital. She went to the emergency department with severe stomach pain and vomiting. She felt the nurses automatically assumed she was drunk: “They treated me like I didn’t know what I was talking about, making it up, exaggerating.” They tried to administer morphine, which she is also allergic to, and she did not receive any additional treatment for her condition. Later, Našuk went to a hospital in another town when the same symptoms recurred. This time the physicians ordered an x-ray and found a stone and a blocked duct. She was immediately transferred to a larger hospital for an operation on her liver. Našuk explained:

The West Coast General Hospital could have done the same, but they didn’t because of their attitude toward Native people. I really wish – this is a huge wish – that this hospital would treat us like they treat everyone else. Talk to us, tell us what

they are doing, what the medications are. Don't leave us in limbo, that's what happened at residential school. Waiting around to be told what to do (interview, June 21, 2018).

The stories of Našuk and her stepbrother describe the discounting of patients' illness narratives and racial profiling, through an exclusionary mode of care. Within health care experiences, personal and family histories of traumatic interactions, such as the non-consensual treatment and abuses suffered in Indian Hospitals, intertwine with present experiences of the failure to adequately addressing suffering and illness.

Exclusionary care is manifest through a broken contract of trust between patients and healers. It is possible Našuk's experience could be interpreted as an honest mistake on the part of attending physicians, who failed to identify the severity of her symptoms. However, regardless of the explicit or unconscious intentions of health care providers, the affects of colonial trauma continue to operate through health care experiences. Due to the power imbalances between patients and healers, "even if a person (in this case health care staff) does not intend to act in a discriminatory manner, his/her historical location as a member of a privileged group is implied by and implies the systemic and historical relations that sustain his/her existing location as a privileged member of society" (Tang & Browne, 2008, p. 124).

Avoidance, Apathy, and Resistance

Health care encounters reflect broader socio-political relations, including how power distribution within a society impacts health care relations and the capacity for individuals to pursue a greater level of well-being (Browne & Fiske, 2001). In Chapter 4, I looked at the systemic violence that shapes discrimination in terms of access to health care through the notion of biopower. Investigations of biopower consider the interconnections between

individuals and systemic processes, as Foucault identified two poles through which biopower was asserted. These include biopolitics, which addresses populations as a whole and anatomo-politics, operating at the level of the individual including their subjective and embodied experience. According to Foucault, the two poles of biopolitics intertwined into new technologies of governance which in turn spawned new spaces for political contestation. According to Rabinow and Rose, these new political struggles began to be waged over three fields of biopower: through truth discourses about human life and health; through population-level measurements and interventions; and through modes of subjectification via practices of the self informed by truth discourses ascribed to health and vitality³⁹.

Drawing from the discussion presented in Chapter 4, biopower can be understood as structurally racist and exclusionary, where the exclusion of some sub-populations allows for increased vitality of the population at large (Foucault 2002). Where Foucault failed to theorize the influence of colonialism in biopower, other theorists have since extended this work. For instance, anthropologist Lisa Stevenson connects biopolitics with colonial psychology in her work with Inuit communities. For Stevenson, what links the centrality of race in biopower to contemporary health care experiences is that colonial

³⁹ It is necessary to avoid equating biopower with any conceptualization of nation-states as holding sovereign authority; “this sovereign power is no longer confined to those who are explicitly agents of the state – it apparently extends to all those who have authority over aspects of vital human existence” (Rabinow & Rose, 2006, p. 202). One can see that biopower extends to include, in the context of primary health care and chronic disease management, not just to health authorities and hospitals, but to clinicians, pharmaceutical companies, non-profit societies, public opinion, and even patients themselves. Rabinow and Rose draw from Deleuze (1995) as well as Hardt and Negri (2000) to illustrate biopower as “flexible, fluid and fluctuating networks of existence” (Rabinow & Rose, 2006, p. 198), describing biopower as neither uniform or unidirectional, but, through a myriad of technologies, institutions, and agencies, is capable of penetrating and creating profound effects on the level of subjectivities, bodies, and populations collectively.

forms of governance organized around a racial hierarchy and associated colonial attitudes continue to be embedded in institutional modes of care. Stevenson demonstrates that in a colonial context seemingly “benevolent” forms of care can be experienced as harmful (Stevenson, 2014). This highlights the historical link between racism as a product of colonialism, an essential logic that supported the displacement of the original inhabitants and imposed racial hierarchy (Allan & Smylie, 2015; Waite & Nardi, 2019; Wolfe, 2006). Like Stevenson who is building on the work of Fanon, I agree that the “psychic life of biopolitics” in a colonial context “works on and through the psyche, in the way the colonial imagination infuses everyday relationships” (Stevenson, 2014, p. 96).

Cree scholar, Billy-Ray Belcourt, theorizes the affective life of biopower as the “production of bad feelings” associated with historical and ongoing settler colonialism which “threaten Indigenous livability” (Belcourt, 2018). I find that the “psychic life of biopolitics,” “bad feelings,” and historical trauma are all ways of addressing the affective life of biopower. In drawing from Sara Ahmed’s assertion that affect shapes how we relate to others, these bad feelings circulate through the way they signify historical memory at the same time as the social conditions of colonialism continue to be lived in the present (Ahmed, 2014). The collective histories connected with the residential school system and Indian hospitals persist through experiences such as long wait times for medical attention, which can exacerbate an existing lack of trust in the health care system. As others have noted, the “social dynamics that racialized people experience on an everyday basis create the backdrop against which they evaluate their current health care experiences” (Browne et al., 2011, p. 338). Seemingly mundane complications such as a switch in coverage to generic medication are experienced in the context of racially

segregating health policy⁴⁰ as well as historical trauma associated with health institutions. As such, changes in coverage, wait times, or the discounting of patients' illness narratives confirm a history of unequal access to health services and differential treatment.

As a result of both explicit and subtle systemic discrimination, as well as past trauma triggered by health care experiences, avoidance of health care was described as a common strategy used to maintain one's dignity and autonomy. For example, clients may be resistant to home care nurses who they feel are not respectful or culturally safe in their approach. An Elder from Ahousaht First Nation explained that:

I've known a few Elders that have blocked them out. Because they don't want to see them anymore. . . The thing that many of them come from residential schools and they don't want to hear that kind of talk to . . . Well, "hurry up!" You know, "get started, start eating!" Giving orders and stuff like that. Something we don't want to hear, especially from a non-Aboriginal person. They might have good intentions, but they aren't cross-cultural trained properly. I know not everybody is like that, but it still happens (interview, February 15, 2018).

Similarly, a woman from Uchucklesaht First Nation explained that:

I was caring for my dad and my stepmom. And just before they passed on, my stepmom did not want the healthcare coming in from VIHA. She didn't like the way they were treating her. Because they came in, to me it's like an authority-kind of figure. But yeah, she didn't like them in her house. She kicked them out [laughing]. "Don't come in here!" (interview, June 13, 2018)

Even in the more central locations in which I worked, such as the city of Port Alberni, there was a pervasive avoidance of accessing health services on the part of Nuuchahnulth community members. There were almost weekly incidences reported to NTC nurses of racial discrimination experienced in the local clinics and emergency department

⁴⁰ Health policies such as those enacted in the Indian Hospitals, but also through the Indian Act which (often arbitrarily) outlines who is considered "status Indian" and therefore entitled to non-insured health benefits.

brought to the attention of NTC staff. The pervasive experience of help not being available, especially in remote communities, paired with the possibility of being faced with discrimination reveals why the NTC nursing staff struggle to support clients who refuse to seek medical care.

C`a?ak, an experienced NTC nurse, empathized with how limited access to services might be perceived as a kind of apathy demonstrated through avoiding, or “giving up” on trying to access care. She reflected on her own sense of privilege and her perspective of clients who face barriers in accessing care, by explaining:

I have not experienced many barriers in my life. Period. But I had [a comparable experience] at the bank when my husband died. [...] it was the first time I have felt like that kind of whatever and it made me wonder, how many times do we turn away somebody and so they just say, “forget it.” So that’s maybe about injectable arthritis medicine. If I am an obstacle, they say forget it. And the outcome of not doing medication in rheumatoid arthritis is devastating cause the joint damage happens. We are trying to stop that. And its irreversible damage once it’s done (interview, March 1, 2018).

Through her explanation, I understood C`a?ak’s example as emphasizing the necessity of a relational approach to health care provision to reduce barriers to health care. However, I do believe that in many cases, avoidance of the health system, or refusing nurses from entering the home is a way of resisting injustice or what is experienced as undignified treatment. Despite being an area of concern in public health, avoidance is also the assertion of autonomy, it can perform a small act of resistance. The assumption that avoidance of health services is the result of apathy mirrors the discussion of bureaucratic indifference and historical blindness introduced in Chapter 4. There, I argued that the lack of access to health services in “remote” communities is seen as rooted in geography rather than the legacy of racially segregated health services and colonial ideas of the

centre and periphery. Assumed apathy, or the failure to appreciate acts of resistance, is another example of how widely circulated discourses help to deflect responsibility to individuals rather than the systemic racism embedded in health care.

NTC nurses seemed to view avoidance of health services as a problem to be solved through the application of persistent and patient relational care, through taking time, connecting with the community, and building trust. This was deemed necessary work, as the immediacy of personal histories in present health care encounters may not be apparent to health care providers working outside of the tribal council. Tang and Brown have addressed the racialization of Indigenous Peoples in health care by exploring the “‘tension of difference’ between perceptions of racialization by patients on the one hand, and the discourses in health care that tend to gloss over or deny its existence on the other hand” (Tang & Browne, 2008, p. 114).

In my own research, specific health care providers or certain sites were often the target of blame for racialized care. In responding to this source of conflict, I consider my role as an analyst is to illuminate some of the broader discourses and social histories that make traumatic and racialized health care experiences a reality for many Nuuchah-nulth-aht. Tang and Brown’s response to navigating this contentious space is to critically examine patients’ perceptions of not having their concerns taken seriously by asking “how such perceptions are reflective of the larger discursive context in which racialized images of Aboriginal people are constructed” (Tang & Browne, 2008, p. 115). Bringing attention to the invisible immediacy of historical trauma is necessary to understanding the lingering affects of health care encounters for many Nuuchah-nulth-aht, or Indian hospital and residential school survivors more broadly. However, there is more to the

situation; health care practices have vastly improved since the era of Indian hospitals, however discriminatory practices continue through more subtle forms.

The Production of Truth

I was thinking about how it intersects, the traumas, the addictions that are the result of the residential school, and how it intersects with mainstream health care services. And they're just... there's all of this talk and hype about being culturally sensitive in a way and they are just at the beginning of addressing it, they're nowhere near getting it right because a lot of the issues are steeped in people's... they don't even know that they're being racist, because it's these habitually taught things, that are systemic (Ticoma, NTC Nurse, February 28, 2018).

My analysis of Ticoma's experience is that the health system "is nowhere near getting it right" because of the circulation and production of discourses that justify the health inequities Indigenous Peoples face. Two examples I have provided thus far are the notion of "remote" as justifying limited access to health services, as well as viewing patients as responsible for avoiding health services, rather than the systemic violence perpetuated through health care experiences. Here, I further unpack how exclusion continues to operate as a normative mode of care by showing that what patients experience as pervasive racial stereotypes are not only ideas which hold currency within health care but are constantly re-produced through standard practices within health care delivery.

Drawing on my conceptualization of biopower, I illustrate how the production of truth discourses, in the form of racial stereotypes or "implicit bias" (Allan & Smylie, 2015), not only constitute the exclusion from public health services experienced by Indigenous peoples but are in fact constructed by or products of specific standards of practice.

There are many myths and stereotypes operating in the public imaginary when it comes to Indigenous peoples and health care. Some of the most common myths documented include the assumption that Indigenous patients seeking care are likely to be

intoxicated (Peters & Self, 2005; Thatcher, 2004; Vowel, 2016) and that Indigenous patients are “misusing” the health system (Waldram et al., 2006). Writing on racialization processes in health care, Tang and Brown argue that stereotypes are products of public discourses which “tend to reify a general assumption that most Aboriginal people come from low socio-economic status, are prone to alcoholism or substance use, have low levels of education, are non-tax paying members of society, and are dependent on social or governmental services” (Tang & Browne, 2008, p. 116).

To give an example of how these racialized assumptions inform health encounters, Našuk recounted an experience she had shortly before moving from the remote village of Kaldonen to Port Alberni:

My daughter displaced her kneecap while in Kaldonen. It took five hours for a rescue boat to arrive. I got hold of the health worker from the band. I had to get a note from the doctor for weekend accommodation because there were no boats until Monday. The doctor said, “you people come into town and expect me to write a note to spend the weekend going to the bar” (interview, June 21, 2018).

Through the manner in which Našuk recounted this story, I could tell she was hurt and offended by the doctor’s response, yet at the same time she told it as an example of a pervasive experience many Nuu-chah-nulth-aht face. Additionally, this story demonstrates the intersection of inequity in both access and quality of health care. The difficulties accessing emergent care to treat a displaced kneecap coincide with racialized assumptions that further pose barriers for the family seeking care. I am in agreement with Tang and Brown that beyond these responses “the ways that people from certain racialized groups are ‘profiled’ have to be understood within the dominating discourses that normalize or naturalize the particular images that the mainstream society constructs of them” (Tang & Browne, 2008, p. 119).

Stereotyping occurs at the interpersonal level, and because it is particular healthcare providers who are flagged by the Indigenous community as being racist or a doctor to avoid, conflicts over mistreatment or discrimination are waged at the level of the clinical encounter. If formal complaints are made, they are generally addressed by the lead staff representative in the facility where the incident had occurred. In some circumstances, complaints are forwarded to larger governing bodies such as the BC College of Physicians and Surgeons, or Quality Assurance councils within health authorities. But the course of action taken to remedy the incident is always determined by an examination of testimony from either party regarding one particular encounter. The role of anti-Indigenous discrimination at the systemic level, and, importantly, how stereotypical assumptions continue to be a normative mode of communicating about or to Indigenous patients is left unaddressed.

Drawing from the understanding of the link between colonialism, biopower, and racism, my aim is to demonstrate how biopower excludes and marginalizes Indigenous peoples by constructing the very stereotypes which are used to justify or explain the exclusionary and dismissive treatment of First Nations patients. In this sense, biopower in the Canadian context produces truth discourses which are materialized through clinical practices, thereby perpetuating the logic of exclusion. Standard practices within healthcare delivery set in motion a series of events that produce scenarios which, in their very design, provide imagery which feeds into and sustains pervasive stereotypes about First Nations people as members of a population. However, none of these scenarios are inevitable or innate to Indigenous ways of being, they are themselves products of current practices and standards within health care delivery.

During a visit to Tla-o-qui-aht territory, situated on the rim of the Pacific Ocean, I was brought into the ad-hoc NTC nursing clinic that was operating at the time in the community. Inside the converted townhome, the living room was set up like any other health centre waiting room with filing cabinets, medical supplies, posters and chairs. A family sat across the room from me. The father made small talk with me, while the rest of the family members were occupied with reassuring the youngest, who was anxious about receiving an immunization. After the family had been attended to, I was led into the small office to chat with Łisnaak, a long time NTC nurse and adopted member of Tla-o-qui-aht First Nation.

One of the biggest problems is dismissiveness on the part of doctors and nurses. People have to travel a long way to see a doctor and often are just told to go home, take a Tylenol and sleep it off. These doctors and nurses don't understand what they have gone through just to get to the hospital. There was this man, we sent him to the hospital because he had very bad pain. The hospital staff gave him morphine and sent him out. He has difficulty walking, he doesn't drive, and it was very late at night (field notes, February 2018).

Łisnaak was alluding to the unnecessary creation of risk, as the hospital was approximately 10 kilometers away from the man's home and much of that distance included highway skirted by dense west coast rainforest.

Speaking of perhaps the same client, or a client in a similar situation – due to patient confidentiality I was not privy to names or specific details pertaining to either case – Ticcma, another NTC serving the same communities described:

There's a gentleman that has chronic pain right now, he's got deteriorating disks in his back and he's been waiting for surgery and he needs to have a pain management plan in place at the hospital so that when he presents, he just gets what he needs and he's treated the same way every time he's there. But he won't voice what he actually needs. We need to like, for example he would come in, he'd get a shot of morphine or something like that and then he gets discharged. He doesn't have transportation to get home, he's gonna walk out the door, like on a rainy day like today, and he's

gonna stick his thumb out and he's gonna wait for somebody to pick him up. And he's like this big native guy who, like he looks maybe a little bit drunk cause he's wobbly on his feet, right? A lot of people aren't going to pick him up. Unless they know him, right? And sometimes that would happen late at night, like ten, eleven o'clock at night he'd be discharged. And it's like, "what are you doing? If you got a free bed keep the guy!" You know? I don't know and it's hard too because not only have I, like, we've talked about it multiple times to people at the hospital, and I'm hoping that this last talk is going to make a difference but... That's kind of one of the cultural things is not, you know, you're not supposed to ask for help but I don't know if it's because of a cultural thing, or if it's because of residential school. So, that's very common amongst a lot of the Elders, is that you have to be strong and you have to provide for yourself and don't ask for help. But you want help and if somebody provides you help then you accept it, but you don't want to say what you need. It's frustrating, and then you know people at the hospital are busy and think that he's seeking [narcotics]. (interview, February 18, 2018).

Ticcmma mentioned how the imagery of an intoxicated (on hospital administered narcotics, no less) First Nations man, hitching for a ride late at night fed into the public perception of Indigenous people as substance abusers taking advantage of an overly compassionate health system. In effect, this man's attempt to seek a remedy for his suffering, and the absence of any substantial or long-term solution, reaffirmed a pervasive public perception that is linked to an oppressive public imaginary. Additionally, "these incidents can have lasting effects in terms of reinforcing and normalizing the 'stereotyping residues' of racial profiling as patients' charts are labeled in particular ways for future reference" (Tang & Browne, 2008, p. 120). This conversation occurred early on in my time with the NTC, but soon came to be an exigent topic of concern. Time and again, similar stories were expressed of Nuu-chah-nulth people embarking on the long and expensive journey from remote communities to seek acute medical attention, only to have their health concerns dismissed and left untreated.

Another, and perhaps more controversial example, is the case of the pervasive stereotype of First Nations patients as drug-seeking paired with a demonstrated over-

prescription of pain medications. During my time at the NTC, many Nuuchahnulth people shared their concerns that doctors were just “pushing pills” instead of looking into the cause of chronic pain, and worried about the use of pain medications as having a negative long-term impact on their wellness. Throughout the stories shared during the Nuuchahnulth Patient Voices Project, it was clear that the commonly held perception of First Nations people as “seeking” – accessing medical services for the sole purpose of obtaining narcotics – frequently led to doctors or hospital nurses sending patients home without a thorough examination with devastating consequences.

Medical anthropologist, Samantha King, has identified how class and race relations in Canada have shaped dominant discourses of opioid use in Ontario (King, 2014). These dominant narratives distinguish between what is presumed to be licit (deserving patients) and illicit use. What King found was this distinction rests largely on class boundaries and how those suffering from chronic pain access medications – whether from a doctor’s prescription paid out of pocket versus from social assistance benefits or obtained from the streets. Panic and punitive measures enacted to deal with substance abuse were projected onto those on social assistance or racialized groups, deflecting blame away from “state-corporate regimes that push pharmaceuticals to the public” (King, 2014, p. 448). What this shows is that racialized distinctions between deserving and undeserving patients have been documented in Canada, coinciding with gender, race, and class hierarchies that have historically underlined colonial power structures in North America. In a similar vein, Browne et al. (2011) address how treatment for chronic pain can become “coloured by prevailing attitudes in healthcare” (339), wherein racialized or socio-economically disadvantaged patients are more likely to be viewed as drug-seeking.

Similarly, health care encounters mirror broader socio-political relations across society, which manifest through implicit assumptions.

In comparing the narratives shared throughout the Nuuchahnulth Patient Voices Project, it is clear that discrimination in the health system is connected to inherent values surrounding who is most deserving of a physician's time within an emergency department. Through these inherent values, which ultimately determine who is admitted first, who is afforded a bed and so on, discrimination manifests intersectionally where, for instance, a First Nations person who is female and a substance user is the least likely patient to receive a thorough examination in an emergency department, often regardless of the nature or severity of illness she presents with. Given the prevalence of dismissal from emergent care based on assumed substance use when First Nations people present with pain, the common practice to either prescribe or dismiss perpetuates the stereotype of misuse and effectively reproduces the stereotype as a reality – from the perspective of health care providers – regardless of the personal history, hopes, or values held by the patient.

In speaking with physicians throughout the Nuuchahnulth Patient Voices project about how discrimination manifests in health care encounters, they often alluded to the over-burdened nature of the health care system. For example, under a fee-for-service model, most physicians are compensated by the number of patients they can see during a shift. In the case of hospitals with a limited number of staff and beds, physicians are encouraged to move along the “easy” patients (those with a quick diagnosis that doesn't require tests or hospitalization) through the system and out of the hospital as quickly as possible. While the hospital is more so a space dedicated to preserving life rather than

increasing vitality, the discourse and lived experiences of the hospital as over-burdened presents us with a jarring example of how in neoliberal and biopower logics of care, exclusion of some becomes necessary to protect the vitality of others. In the emergency department, not everyone will have an opportunity for a thorough examination, and if an “easy” diagnosis can be made that an individual is either drug seeking or can “go home and take a Tylenol” (to cite a common yet frustrating experience), they will be sent home.

However, these fast judgements between “easy” diagnosis and patients requiring more extensive care are often laden with implicit bias. One physician working in the northern region explained that:

We do have people who come in who are drug seekers who are repeat offenders who don't look after themselves and then sometimes the label for these people who are actually misusing the system, it gets labeled on top of other people, particularly when people are tired and they're trying to run stuff through the system. And you can see it in GP practice. ‘Cause I understand like they give six minutes to every patient . . . I believe like in some of the emerges, there's hundreds and hundreds of patients going through every day to two or three physicians and there and a lot of the instances they're dealing with are life and death and they're trying to cherry pick out the life and death ones that they'll make a difference and try and get everybody else to go off and see your GP (general practitioner) in a couple of days (interview, June 2, 2019).

While the physicians were apt to admit that some patients may be mislabeled as “drug seeking” they remained steadfast in the judgement that “some” patients are in fact drug seeking. However, as discussed, reliance on previous charting and assumptions tied to the appearance of some patients can lead a physician to believe that they are making an accurate judgement to send a patient home, effectively silencing and dismissing the lived experiences of the patient.

In an ethnographic study with patients and emergency department staff at an urban hospital in western Canada, Tang and Brown found that Indigenous patients

interviewed wondered whether their experiences were negatively shaped by their “racialized background” whereas health care providers asserted an “egalitarian discourse” (Tang & Browne, 2008). This discourse - that “‘everyone is treated the same’ irrespective of the patient’s background or social positioning” – makes it very difficult for health care providers to recognize the existence of racial discrimination in their workplaces (Tang & Browne, 2008, p. 110). These conflicting views reveal the political nature of how health care experiences are interpreted, as these experiences intersect with broader social and historical dynamics that shape the way individuals make meaning from their experiences (Browne & Fiske, 2001; Tang & Browne, 2008).

Indigenous scholars have criticized this egalitarian discourse, or the idea of equality as defining a Canadian national identity, as actually whitewashing the colonial history of racism in Canada (Allan & Smylie, 2015; Vowel, 2016). Throughout the Nuuchah-nulth Patient Voices Project, physicians interviewed tended to historicize the patient narratives as if they occurred in a distant, more troubled past, when in fact many stories were experiences from the past year. Another common response from doctors when confronting stories of racism in health care was to try to tease out how the health care system is limited for *all* patients. Again, the egalitarian discourse is evoked to explain that some of the complaints coming from First Nations patients are maybe not based in racism but just in an over-burdened system.

Additionally, physicians tended to discuss the potential for care practices shaped by racism as varying between health care providers, emphasizing the need for everyone to have equal training. For instance, one general practitioner explained that:

I think that providers, some of us are trying really hard in every encounter we make and we need to work harder as a profession to make sure that all of our colleagues have this education, realize the importance of this, realize the systemic issues behind all of this and just take the time. Because yeah, I think what you and I come at encounters with is not necessarily, unfortunately, 100% what all our colleagues do. And that's not fair and that's not good. And we need to have better expectations of our other colleagues and we need to hold them up to those standards (interview, June 15, 2019).

This approach tends to individualize the problem of exclusionary care rather than seeing it as embedded in societal structures. Stereotypes, and the production of scenarios that fulfill stereotypes through specific standards of practice, allow for a justification of who is deserving of thorough medical attention and who should be sent away.

In setting the common stereotypes and scenarios that are imposed upon Indigenous peoples in western Canada within the context of Canada's colonial history, it becomes apparent that such imagery is rooted in long standing racial bias that sustained colonialism through the oppression of some to the benefit of the colonizing population. Systemic racism underlies public perceptions about racialized groups that are enacted in clinical encounters, such as dismissing a patient's pain under the assumption that they are "drug seeking." These broader social-political dynamics often manifest as implicit assumptions on the part of health care providers. Care practices that are informed by these implicit biases work to construct and reinforce pervasive stereotypes, such as sending a chronic pain patient home on narcotics, without assistance returning home and no long-term care plan to manage his symptoms upon returning. In cases such as these, if dependency on pain medications were to result, it would likely be considered to be a fault of the patient's own character (e.g., "they don't look after themselves"), rather than the failure of the health care system to adequately treat chronic pain.

These pervasive ideas represent a truth discourse that is both enacted through clinical encounters through decision-making on the part of health care providers as well as constructed through care practices such as dismissing patients' illness narratives or not responding to patients' lived circumstances. Additionally, pervasive discourses such as "we treat everyone the same" further mask experiences of discrimination in health care. Health care systems in Canada cannot be understood as homogenous or unitary and it would be false to essentialize all health care providers as self-motivated agents of oppression. However, health care providers work within structures and historical processes that have operated as techniques of colonial oppression.

Understanding and Relational Care

In discussing experiences of discrimination in health care, one comment that was repeated often by community members was about a failure on the part of health care providers *to understand*. For instance, at several public meetings I attended on the topic of improving health services, it was often discussed how the Canadian government or established health care system "doesn't understand who we are as a people." Conversely, NTC nurses were commonly described as genuinely trying to understand and respect Nuuchahnulth ways. More specifically, health care encounters that did not successfully lead to the alleviation of suffering were often explained through a lack of understanding.

On a grey February day, I visited the home of Țamuuk and Țiškiiiku on the Tseshahht reserve⁴¹. Sitting in the warm and lowly-lit living room, Țamuuk discussed ongoing challenges with accessing care for his wife, Țiškiiiku, who suffered from

⁴¹ Tseshahht First Nation is located along Highway 4, about 5 kilometers from the city of Port Alberni.

rheumatoid arthritis, fibromyalgia, and a recent cancer diagnosis. Despite his own health limitations, Tāmuuk described his daily efforts in making life comfortable and fulfilling for his wife. He expressed frustration with the couple's efforts to find a supportive pain management regimen. Apparently, after a change in doctors, Kīškīiku's pain medications had been increasingly reduced. Occasionally, Kīškīiku has visited the emergency department seeking relief for her pain but was met with doctors who were hesitant to help. The couple believes this is linked to assumptions about drug misuse and a failure to understand. Tāmuuk said, "if the doctors could only walk two days in my wife's shoes, then they would finally understand how it is to live with chronic pain" (interview, February 22, 2018).

Recently Kīškīiku has been noticing issues with her hand jerking, but they have been unable to follow up with a doctor because they have been focused on dealing with her cancer diagnosis. Tāmuuk is also concerned because it is getting harder for him to get her to the hospital as he suffers from emphysema. He showed me the various coffee thermoses and water bottles he has rigged to that Kīškīiku can continue to enjoy coffee, water, and other beverages without spilling on herself. Tāmuuk regularly attends his wife's doctor appointments because, he states, she is afraid of doctors and feels more comfortable when he is with her. As well as support, he offers advocacy to ensure she has adequate care. Due to this, there have been instances where doctors would not allow him in the examination room. The couple recently received an apology to a letter of complaint. Tāmuuk commented that, "it is my biggest pet peeve; if something is wrong and I know it, I'll fight it and a lot of times that means fighting for my wife's health" (interview, February 22, 2018).

Pervasive racialized stereotypes associated with Indigenous peoples prevent health care providers from adapting their treatment to the lived realities of patients. The preoccupation with pain medication addiction and misuse prevents prescribers from providing treatment options that adequately address how chronic pain impacts daily life. During a conversation with a Nuu-chah-nulth spiritual healer, this failure to know and understand patients on the part of health care providers was described as: “just like anywhere else, there's always a bad apple that works in the environment place. Always. RCMP, teachers, doesn't matter. Someone. That's ignorance of don't know who the other person is. That's all it is. Ignorance of not knowing who that person is” (interview, May 21, 2019). From my understanding, the suggestion is that “bad” doctors can be equated with a failure to understand who an individual is on their own terms, a failure to incorporate a patient’s lived reality into care decisions, or what I discuss here as the limits to intersubjectivity⁴².

The failure of health care providers to understand the lived experiences of Nuu-chah-nulth patients manifests through stereotypes and implicit bias towards Indigenous patients, a failure to acknowledge the impact of historical trauma, as well as a failure to acknowledge the challenges of accessing care at all, for those living in remote communities. Similarly, NTC nurses highlighted that during discharge from hospital,

⁴² Anthropologist Michael Jackson has elaborated on how intersubjectivity should remain central to ethnographic analysis. He states, “we must not misconstrue intersubjectivity as a synonym for shared experience, empathic understanding or fellow-feeling. For my purposes, intersubjectivity embraces centripetal and centrifugal forces, and constructive and destructive extremes without prejudice” (Jackson, 1998, p. 4). Thus, what we may co-construct intersubjectively with those we encounter through acts of care can range from affirmation and compassion to conflict and dissonance. I agree and would like to add that we might also take into account the limits of intersubjectivity, perhaps the extreme manifestation of dissonance, where what is constructed in common is imposed by one onto the other (such as a reduction in medication), or perhaps even abandoned (‘go home and take a Tylenol’).

there is a failure to plan around how a patient recovering from surgery, heart failure, and so on, can actually navigate the trip home on long and rough logging roads and in and out of boats, or the lack of consistent personal support or wound care available in remote communities. The failure to plan discharges relates to the experiences of being told to “go home and follow up with your doctor in a few days” as both instances reveal a failure to recognize how difficult it can be to see a doctor for those living in “remote” communities. With a presumption that “everyone is treated the same” by the health care system, the challenges in accessing care faced by those living in remote communities or facing racial discrimination are rendered invisible. According to Kurtz et al., this “silencing of voice” is an act of structural violence (Kurtz et al., 2008). What is needed in these instances is a sensitivity to the limits of intersubjectivity.

The limits to understanding in the context of suffering has been a long-standing preoccupation in western philosophy. Medical anthropologists have investigated the failure of language to express pain; “the incommunicability of pain arises from asymmetry of access to experiential knowledge that it gives us. According to this view, to be in pain is to be certain about this knowledge. To be asked to react to another person’s pain is to be in doubt about its existence” (Kleinman et al., 1997). This perspective centres around the question of to what extent we can really *know* the pain of another or authentically relate to their experiences.

The anthropology of social suffering has contributed by shifting focus around certainty and doubt of the suffering of others to how:

suffering is produced in societies and how acknowledgement of pain, as a cultural process, is given or withheld. After all, to be ignorant or incapable of imagining another person’s pain does not signal blindness in moral sensibility in the same way

in which the incapacity to *acknowledge* that pain does. Yet this latter failure is at the bottom of the cultural process of political abuse (Kleinman et al., 1997).

In other words, an anthropology of social suffering holds that what matters is not what we can *know* of the pain of others, but our capacity to *acknowledge* and respond to it.

Hannah Arendt's distinction between knowing and understanding supports this claim.

Arendt states that:

understanding, as distinguished from having correct information and scientific knowledge, is a complicated process which never produces unequivocal results. It is an unending activity by which, in constant change and variation, we come to terms with and reconcile ourselves to reality, that is, try to be at home in the world (Arendt, 1994, cited in Parekh, 2008, p. 5).

In the example of Ĥamuuk and Ķiškiiku, living with chronic pain was debilitating and dehumanizing. While the doctors they had sought relief from can “know” Ķiškiiku's condition through diagnostics and assessing risk factors (including risk factors for addiction), they failed to understand what it is to live in Ĥamuuk and Ķiškiiku's world, a world shaped by persistent distress. This failure to understand implicates a failure to acknowledge and respond to pain.

Anthropologist Michael Jackson's conceptualization of intersubjectivity includes the experiences of “being” and “nothingness” as hidden potentialities embedded in every encounter (Jackson, 1998). Being represents the experience of choosing and acting, whereas nothingness represents the deficit of choice, “it is the by-product of being reduced to passivity, of not being able to do or say anything that has any effect on others, or makes any difference to the way things are” (Jackson, 1998, p. 17). Clinical encounters, beyond failing to effectively treat acute physiological suffering, also can produce harm through the failure to acknowledge pain, and through this failure produce

an experience of “nothingness” in the sense that a patient’s suffering is not addressed. This involves the superimposition of a clinician’s own assumptions -experiences of “being”—above the lived experiences of patients, removing their capacity to decide and act. Failure to understand a patient’s lived experiences and the resulting experience of misrecognition produces embodied memories akin to experiences of oppression in residential schools and Indian hospitals. In the case of implicit bias and racialized stereotypes, these interpretations are superimposed over the patient’s own lived experience.

I am in agreement with Veena Das⁴³ that an anthropology of suffering should ultimately be about how pain is responded to, not whether or not it can be rendered intelligible (Das, 1997). When we choose to seek to understand experiences of discrimination in health care rather than to know them, the objective and outcome of our work shifts; “the issue is not empathy but the capacity to pay attention, to be able to hear the words of pain in a way that calls for tact and delicacy and an understanding of one’s own finitude” (Das, 2015, p. 211). Similarly, Sara Ahmed argues that empathy can work to sustain difference, in that that we feel empathetic only when we don’t share the same experience and that empathetic sentiments often work to absolve us from our culpability in the suffering of others. Instead, “an ethics of responding to pain involves being open to being affected by that which one cannot know or feel” (Ahmed, 2014, p. 30). The failure to respond to pain, to seek understanding which can inform action, is an act of violence.

⁴³ Das is writing on the violent abduction of women during the partition of India and its aftermath (1997) and on medical pluralism in impoverished neighbourhoods in India (2015).

This is because, when presented with an expression of pain, we are faced with the choice to acknowledge it or deny it. Choosing to not respond “is a silence that perpetuates the violence of pain itself” (Cavell, 1997, p. 94)⁴⁴.

I consider the co-construction of understanding, of a kind of commons (Arendt, 1958) in health care encounters, as a precondition for relational modes of care. In Chapter 3, I described relational practice within the NTC nursing services as ensuring that the relationship between the care provider and client takes primacy in every health care encounter. This philosophy was enacted by NTC nurses by taking time with clients, fostering trust, building connections with communities, and advocating on behalf of clients. The NTC nursing services were acknowledged by clients as a remedy to discrimination and trauma associated with health care through the culturally safe, relational, client-directed and culturally informed nursing approach. However, though experienced as separate from “mainstream” healthcare, relational modes of care do not exist in isolation from biopolitical structures of care.

C’a?ak, an NTC nurse, described helping a non-Indigenous hospital nurse to better understand the pretenses under which Nuuchahnulth children are brought to hospital, influencing a shift in perception that led to a more supportive approach.

There was an emerge nurse from Port Alberni we had an exchange coming through. And Port Alberni is pretty tough in that hospital and there is a lot of entrenched racism in Port Alberni. Most nurses that came, came because they already loved First Nations and that rootedness and they were just excited to come to Ahousaht. But this one nurse, she said, "those mums, they bring their babies into emergency and they are not even sick!" And I looked at her and I said, "so I don't know if you know this but the numbers of infant mortality amongst Nuuchahnulth is much

⁴⁴ This responsibility extends not just to health care providers but also to the scholars who study experiences of suffering in any form. So long as the social sciences fail to respond to pain, this silence further “extends the violence it studies” (Cavell, 1997, p. 94).

higher than non-Nuu-chah-nulth in our area." So, I said to her, "so, they know their children die. They don't necessarily know why." And she looked at me. And I said, "so every mom that brings their child to you is a very good mum." And she looked at me again. And she got it. You know like, it's just that, "Oh!" So, I said, "the more you can support her as a mum, the more you can teach her about when to bring her baby, what to look for, what that looks like. Make sure your door is open to her. You've just saved a baby. And maybe more. But..." And she just, you know the pieces are so simple and she herself will know of the infant mortality. She herself will see those babies that show up in emerge who are sick or have died. But someone needed to tell her that and it was really fun for her, just to see that light go on and her go "oh! That's true isn't it!" And lots of us do not know the answer to that infant mortality question. It's not like the answer to that is simple. So it's pretty hard to take your baby that you are worried about to the hospital if someone doesn't welcome you. (interview, March 1, 2018).

In this case, the visiting nurse from Port Alberni fell upon the common stereotypical tropes of First Nations people perceived as “abusing the health system.” Through conversation, C’a?ak explained how public health information had influenced the mother’s response – through the known risk of infant mortality – thereby causing a shift in the nurse’s perception which would later influence her practice. This example shows how health care providers are influenced by norms and standards in health care which are structured through biopower. Relationality, in the sense of being present in the community and knowing the social context, allowed the nurses to see beyond the “easy” diagnosis to send her home without examination.

There remains a stubborn willingness in both academia and within healthcare to “know” about healthcare experiences as if what patients experientially endure can be extracted as an object to be known, and therefore afforded labels, definitions, and strategies. This represents a form of “cognitive imperialism” (Battiste & Henderson,

2000)⁴⁵. Sometimes knowledge is co-constructed through encounters (such as building the shared understanding of a particular ailment through dialogue between patients and healers). However, sometimes lived experiences are irreparably incommensurable without shared lived experience. To ignore such a claim, as asserted by patients, becomes an act of asserting one's own interpretation over another's. Recognizing the limits to intersubjectivity is not an easy thing to do because often when those limits are reached, we fill them in with our own interpretations and personal imaginings. Within health care encounters, the power differentials place those holding power in a position to impose their own narratives. Yet they are also the ones with the least at stake when confronting the limits of intersubjectivity, while those seeking care are affected by the limits of intersubjectivity profoundly. Confronting the limits of understanding, they confront the limits of having their pain acknowledged and cared for. For those who are in the position of power in these encounters, it is easy to walk away without considering the limits of their own understanding because that limitation often will never have an effect on them (outside of the potential of gaining awareness that a patient has not recovered or when official complaints are made). This highlights the importance of recognizing the moments where intersubjectivity reaches its limits. This requires shifting the objectives held by health care providers (and researchers) from seeking to know, study, and fix to seeking to

⁴⁵ Battiste and Henderson define cognitive imperialism as a Eurocentric quest to uncover "universal" definitions which can be used to categorize, measure, or manipulate objects of study. These uncovered definitions are assumed to be implicitly superior and are therefore imposed on other worldviews. I extend this concept to the realm of health care experiences as it informs the relationship between experts and patients to the extent that "knowing" a disease subsumes an assumption that physicians must or can also "know" what a patient is experiencing.

understand, as in Arendt's unending process of rectifying ourselves with our shared lived reality.

Conclusion

In summary, avoidance of health care services is pervasive in First Nations communities in western Canada because of the constant reminder that help is not available, whether the travel to access acute care is too arduous and costly or whether through discrimination in an emergency department triage. Shedding light on systemic racism requires uncovering the links between interpersonal disputes and systemic processes, as well as recognizing how specific examples of the failure to understand are linked with broader discourses and practices. Failing to make these links when addressing racism in health care can fuel conflict and prevents the identification of sustainable solutions by perpetuating discourses that deflect the blame for negative health care experiences onto patients. For instance, the tendency to avoid health services should be understood as a response to unresolved historical trauma sustained by recent experiences of discrimination in health services. Standard care practices such as overprescribing and discharging patients without a care plan must be seen as reproducing the stereotypes, such as that Indigenous patients are "misusing" the health system, which are used to distinguish "deserving" and "undeserving" patients in hospital triaging. The discourse that "everyone is treated the same," can then be replaced by the realization that racialized implicit bias pervasively informs health care decision making.

Presently, when complaints are placed, individual experiences of discrimination must be subjected to investigation. Likewise, at the level of discourse, experiences of discrimination are often explained away as the result of an over-burdened health care

system that is limiting to *all* patients. In the era of reconciliation, trauma must be *proven* in order for public processes of reparations to be activated (Million, 2013). National commissions are necessary to shift the public perception on experiences of trauma from refutable claims or attempts to manipulate the system to accepted truths. However, in spaces where understanding remains elusive, causing this shift from public denial to acceptance is a monumental task. Shedding light on experiences of systemic racism produces a kind of shock to commonly held Canadian sensibilities such as equality and universal access to health care. As Indigenous scholar, Dwyane Donald states: “at the heart of the lovely story of the Canadian nation and nationality is a deep denial of the physical, epistemic, and ontological violence committed against Indigenous peoples and their ways. This denial makes it difficult for most Canadians in the present day to understand the complexities of the relationships today” (Donald, 2012, p. 547).

Instead, taking the relations between lived histories and present affects as empirical evidence urges health care providers to stop dismissing instances that might conveniently be categorized as “drug seeking,” “misusing the system,” or that “everyone is treated the same.” This is necessary, as discrimination in the form of implicit bias produces a form of apathy on the part of health care providers, perceiving that they would be unable to help a patient who has been automatically pathologized. It is possible to link this clinical apathy with the bureaucratic indifference that structures inequitable access to health services in remote Indigenous communities. Both present a pervasive failure to recognize and respond to suffering in the form of chronic pain, acute illness or injury, historic trauma, and effective management of chronic disease. As a result, biomedical modes of care are exclusionary towards Indigenous peoples, through inequitable access to

services, the lingering affects of historical trauma associated with health care, and ongoing instances of racial discrimination.

During my research, I had several opportunities to speak with health leaders at the regional and provincial levels about the issues of lack of access and discrimination in the health system. What I found is that in the era of reconciliation, the response to this kind of conversation is a heartfelt acknowledgement coupled with an overview of all the things they are currently doing better, whether it is opening a community gathering space in the hospital, hiring cultural safety coordinators, or a new strategic plan. While these changes are by no means insignificant, I remain concerned with the possibility of these declarations of positive change as an erasure of the systemic nature of racial discrimination in health care. In speaking with Nuu-chah-nulth-aht, an opinion frequently presented to me was that it is hard to imagine how small changes in the mission statement and a few more staff members can amount to substantial changes to the pervasive experience of being told ‘no, help is not available.’ Harley Eagle, a former cultural safety coordinator for Island Health, stated that in the context of truth and reconciliation, more time is needed to allow the truth telling to unfold before movement can be made in the era of reconciliation, especially in the area of health care. If I can humbly add to this wisdom, I would also suggest that acknowledgement should be made to the relational ways care is provided and health is sustained, that operate outside and alongside the biomedical health system. In the case of NTC nursing services, the foregrounding of Indigenous modes of care mitigates historical trauma and contemporary experiences of discrimination through prioritizing relationships and understanding as key to effective

care. In other words, Indigenous modes of care are both marginalized by and challenge exclusionary biopolitical forms of care.

Towards the end of my field work, I was sitting with T`ašii on her porch in Tsaxana on a drizzly day with hummingbirds buzzing by. She was imparting her wisdom about the human need to move away from past trauma, or “being stuck in a state of survival,” and towards spiritual enlightenment.

Megan: I just have one last question about that. Do you see doctors as having a role in achieving that [emotional and spiritual healing], and what would that look like?

T`ašii: Yeah, that's when you're talking about cultural safety and that's really being aware of, and just like I was saying, people need to know where they work, where they live. The doctors need to know their neighborhood, they need to know their hood and understand about the ... Well, if you're going to be here for any length of time, know about the governance system, know about the community, know about all the things our people have gone through. The whole issue about oppression and all that, they need to be aware of all that, to understand the people. How can you serve those people that you don't know about? That makes no sense. Medicine is not just band aids anymore. It's that holistic understanding that the doctors really, and the nurses, anybody in the healthcare system needs to know.

Chapter 6: Collective Ontologies of Care

On a bright spring day, I stood at the edge of the surging Somass River bordered by shrubs and wildflowers. The sun peaked through scattered showers creating ethereal beams of light. Standing around me were members of the NTC nursing team. I was a bit unnerved with the idea of participating in ceremony with women whom I admired; to be vulnerable in front of my mentors. My daughter stood by my side. Two women from Quu'asa had come to perform the ceremony and had arranged the site with items that would be used in a sequence to cleanse and heal each of the nurses, with myself included.

It was a brushing ceremony organized for the NTC nurses. In a cleared area on the lawn, the Quu'asa workers had set up a hoop that was adorned with spruce, followed by a bamboo mat laid on the floor, followed by a second hoop with cedar branches tied to it. We all stood in a line along the outside of the cleared area, all facing towards the hoop and took our shoes off. Many of the women had their eyes closed and stood stately. One of the cultural workers explained that the spruce was used to clear away negative energy and thoughts, all the pain we were ready to leave behind. The mat was placed to pray for the good we had in our lives before, but had lost track of, and the cedar was to protect us moving forward.

Standing in a group in the open space, we each took a turn passing through the sequence, which finished with each participant taking a place holding a long cedar rope woven into a large hoop. A cultural healer shook a rattle for each of the nurses in turn. My daughter was invited to take part; however, she was excused from participating in the

first step as it was too powerful and unnecessary at such a tender age. I watched her pass through the latter phases, with a sense of pride in her ability to take reverence in this new experience.

When it was my turn to pass through the sequence, I stepped towards the woman with the hoop. The rattling became louder and louder until its rhythms seemed to consume me. As I passed through, the woman gently brushed my body with spruce bows, deliberate, focused and with a tangible kindness. However, in the moment it was not the act of generosity that moved me. I felt my face trembling. What proceeded as I passed through from the spruce bows to a cedar hoop, was a very visceral unwinding of the tensions embedded in my core sense of self. I began to weep but this was inconsequential to what we were all creating together in that moment through the will of the cultural healers. I felt a weight had lifted off me, my feet felt firmly planted and I felt as if I were standing taller. I walked through and joined my daughter on the prayer mat. I wiped my tears as I took my place along the woven cedar rope that held all participants together in a circle. The sun beams through the spring showers lit gleaming patches on the heads of the nurses. My privately shed tears of release mixed with rain drops which then disappeared into the mossy earth below our bare feet. We all laughed when one of the nurses accidentally split the cedar rope in two, and promptly tied it back together.

Figure 8: Brushing ceremony attended by NTC nurses, May 24, 2018

Thus far, I have laid out the evolving configurations of Indigenous health governance in Nuuchahnulth communities, and described the relational modes of care as practiced by Nuuchahnulth nurses, understood in contrast to the historical and ongoing context of health inequity that is part of the colonial project of the Canadian state. I have also spoken to ongoing targeted violence within mainstream health care and how these structural processes are imbricated within interpersonal healthcare experiences. In this chapter, I address another layer of care in Nuuchahnulth communities by describing

some of the specific forms of attending to one another's health that exist alongside, outside, or in tension with biomedical procedures, colonialism, and western worldviews. Rather than illuminating systems, discourses, and modes of practice as I have done in other chapters, I share an account of some of my experiences and observations of collective and relational modes of care. As such, this chapter explores the affective and ontological dimensions of informal care in Nuu-chah-nulth communities⁴⁶.

In Chapter 3, I described the NTC nursing relational practice as requiring reflexivity of the nurses' own bias and assumptions, taking time, fostering trust, building connections with communities, and advocating on behalf of patients, with a focus on how the ideal of relational care might be translated into Indigenous nursing practice. Here, I focus on shared community spaces and family homes as sites of care and healing. I explore examples of care as ontologically relational through community gatherings and circulating values and ideas around familial love and responsibility. I draw from Nuu-chah-nulth *hahuupa* (teachings) that have been shared with me to illustrate ontologies of healing and care which are collective in nature. Lastly, I consider the contemporary material implications of these ontologies, by looking at tensions surrounding care obligations for older relatives in communities with limited access to health services. In my analysis, I focus on the ontological and affective implications of relational care.

⁴⁶ This is one of the most difficult chapters of my thesis to write while keeping true to the theoretical and ethical commitments I have made to myself and research participants. As such, it is necessary to note that this chapter reveals a series of inferences and interpretations that are the product of my own contemplation on events and conversations and do not offer any generalizable or definitive answers on Nuu-chah-nulth culture or identity.

Ontological relationality recognizes the interconnection of all beings, the land, and the spiritual world. Care, in a relational worldview, implicates the responsibility inherent between those caring for and being cared for. By looking at relationality as an ontological premise, reality is contingent on relationships that suspend between individuals within the community and within the cosmos, in a web of obligations and accountabilities (Wilson, 2008). As such, relationality is a distinctly ethical mode of being. Care as collective reveals the persistence of connectedness through bounded acts of care, as well as through the haunting persistence of grief, to reveal care as something more than a temporally-situated transaction or sentiment.

Ontologies of Care

As outlined in Chapter 1, I view care as the production of local moral worlds, which configure the materiality of how those cared for are attended to and their affective experiences. Interrogating modes of care offers insight into how relationships and encounters with the intent to invoke healing (whether within families, hospitals, clinics, or at the level of populations), can be enacted in multiple ways and therefore bound up in multiple and perhaps divergent logics of pertaining ethical obligations. As previously stated, Borneman illustrates how an ethnographic attention to modes or practices of care can provide a non-essentializing way of understanding how groups organize affiliation (Borneman, 2010). As impactful as this argument has been, my interest moves beyond social organization to explore how modes of care may invoke potentially transformative affective states from grief or trauma to hope and connection. I believe care is also an important site for ethnographic exploration because it shifts the focus away from health

care perceptions or abstracted knowledge about health and how healing occurs to how people are attended to through care encounters.

By exploring the ontological and affective dimension of care, I must first clarify that this discussion is not an attempt to reduce Indigenous and biomedical modes of healing as neatly contained within distinct and incongruous worlds. Such an approach, common within the ontological turn in anthropology⁴⁷, relies on long-discarded ethnographic techniques such as describing cosmologies as isolated and bounded, and collapsing cultural change and adaptation into the ethnographic present (Starn, 2011). Such an approach would inevitably reduce Nuu-chah-nulth modes of healing to an essentialized set of practices that would not be representative of how care and healing are often described as diverse and individualized within these communities.

Alternatively, we might instead understand different modes of care as the subject of multiple, coexisting ontologies, such as in the work of Annemarie Mol on competing diagnostic ontologies of cardiovascular disease in a Dutch hospital (Mol, 2002). As such, one could explore how ontological politics shape practice (and as practice also works to inform ontology), thus exploring how the tensions between ontologies of care impact the ways in which patients are attended to. Mol describes how in treating the same disease, different specializations enact different diagnostic results of the presence of disease in a patient, thus leading to sometimes contradictory courses of treatment. Revealing the existence of multiple ontologies is instrumental because it illuminates the persistence of ontological politics, which are, for Mol, “a politics that has to do with the way in which

⁴⁷ For instance, in the works of Eduardo Viveiros de Castro (1998), or Mario Blaser (2009).

problems are framed, bodies are shaped, and lives are pushed and pulled into one shape or another” (Mol, 2008: viii). Furthermore, while ontologies work to shape lived realities, they are also brought into being and sustained through practice; “*ontology* is not given in the order of things, but [...] instead, *ontologies* are brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices” (Mol, 2008:6). In this way, I do not aim to prescribe what exactly it means to care for another faced with illness in a Nuu-chah-nulth context, but rather to contemplate how this question is being implicitly answered many times over through conversation, voicing expectations, and ritualized social practices such as the brushing ceremony. In other words, ontologies of care exist through practice, and therefore care becomes known through the iteration of actions recognized as forms of care. However, the process of performing care and recognizing it as such shifts with every iteration. Modes of care and how they are received are contingent on the kinds of culturally informed logics healers, patients, and their professional and familial relations bring to bear on the situation (Garro, 2000; Kirmayer, 2000).

Attention to multiple ontologies of care requires an understanding of the affect relating to care experiences as socially circulating. In this sense, I take insight from Raymond Williams’ “structures of feeling” (Williams, 1961). For Williams, structures of feeling are the active “alternative social characters” that in complex and diffuse ways affect “the whole life of the time” (Williams, 1961, p. 83). In this way, the structure of feeling corresponds to the interplay of dominant and alternative “social characters,” and their affective and socio-material implications. I extend structures of feeling to think about how the circulation of ontologies of care influence the ways care manifests in Nu-

chah-nulth communities and how it is experienced. Many of these ontologies of care can be traced to pre-contact ways of life, however they also currently operate in response to contemporary social conditions.

Exploring ontologies of care requires taking seriously unfamiliar forms of knowledges. As such, I take inspiration from Paul Nadasdy's call for ethnographic agnosticism (Nadasdy, 2007). This requires taking literal the words of informants and refusing to dismiss the possibility of dimensions of nature that exceed what may be considered "rational" through Eurocentric scientific frameworks. Beyond the "standard ethnographic suspension of disbelief," (p. 37) this necessitates a "willingness to treat extraordinary experiences as data and take them into account in our theory making" (Nadasdy, 2007, p. 37). As such, ethnographic agnosticism implies a political commitment by taking literal what has previously been categorized as 'cultural constructions' or purely symbolic or metaphorical elements of healing.

For instance, there is a longstanding tradition within the discipline of anthropology to analyze the collective emotions that are produced via public rituals (Durkheim, 1982; Turner, 1970). Anthropologists have been interested in describing how "in collective healing rituals there is a merging, a communion of mind/body, self/other, individual/group that acts in largely non-verbal and even prereflexive ways to 'feel' the sick person back to a state of wellness and wholeness and to remake the social body" (Schepher-Hughes & Lock, 1987, p. 29). Often in these writings, the potency of collective healing rituals is attributed to what Lévi-Strauss has termed "symbolic efficacy" (Lévi-Strauss, 1963). Symbolic efficacy presumes that "through the use of a web of metaphors, the ritual transposes the present event onto a symbolic plane and thus into a larger

collective story” (Das, 2015, p. 176). This psychological manipulation through the use of metaphor can induce a response in a shaman’s patient, by empowering the individual in connection to a higher collectivity. The issue I take with symbolic efficacy is that it discounts Indigenous knowledge by dissecting and reframing ritual processes and their meaning in a way that becomes coherent to a Eurocentric worldview. Again, I am interested in exploring ethnomedicine literally rather than metaphorically. Attention to ontologies of care imply how care practices and their affects constitute the reality of those participating.

Another issue I take with symbolic efficacy is that it tends to subsume individuals as composing a homogenous collective structure. Contrary to this, it was repeatedly emphasized to me that how and to what degree Nuu-chah-nulth-aht participate in culture is an individual choice and varies among families. My understanding is that care as a collective phenomenon exists somewhere between the emphasis on the collective and an appreciation for diversity, individuality, and autonomy. Perhaps these things need not be understood dichotomously. Ticcma, an NTC nurse, explained this to me with a greater depth of clarity:

Well, you know some things are kept secret. There's secrets that are kept within families, there's secrets that are kept within immediate families and then there's secrets that you keep to yourself, because they have power for you. I was talking to an Elder about prayer. Like how do you pray? What do you do to pray? And like you can be taught to pray but really what I got from it was you have to create your own way of praying. I think I remember being told a story about somebody's father that would go and do ceremony or prayer all the time but he never let anybody come with him, it was always, it was his thing that he did, and he never told anybody what he did but it gave him strength to do it, right? So there's that kind of secrecy, there's secrecy in the richness of your own being, you know like, it has to do with taking care of yourself if you really get to know yourself and love yourself, there's going to be things about yourself that you don't need to have acknowledgement, you don't need to have acknowledgement from other people to

be who you are and what you do ... And I think that's something that's promoted in the Nuu-chah-nulth culture (interview, February 18, 2018).

According to many of the people I spoke with, culture, spirituality, and healing are things which individuals explore in their own ways. While maintaining an appropriate level of secrecy is tied to the potency of spiritual endeavors, valuing privacy also promotes individual autonomy, that each person has a right to uncover their own means of fostering spirituality.

This is akin to the principle of noninterference, which Anishinaabe author Calvin Morrisseau describes as the allowance of “members of society to experience life in each their own way, thus creating a reality based upon their own experience” (Morrisseau, 1998, p. 5). The principle of noninterference also implies that, while there may be prescribed cultural protocol, there is no one definitive way to practice Nuu-chah-nulth spirituality or embody Nuu-chah-nulth culture. For instance, during casual conversation with a Nuu-chah-nulth friend, she explained that “it’s impossible to say, ‘that’s what Nuu-chah-nulth people do’ or ‘that’s how they are’ because there is no one way.” Her concern was that ideas about Indigeneity can become “a bit indoctrinated” in that things must always be done a certain way. However, “in Nuu-chah-nulth there is a recognition of individuality and that each person, each family, has their own way of doing things” (personal communication, April 19, 2019).

This also translates to the range of opinions that exist regarding traditional medicine. Many families are invested in the resurgence of Nuu-chah-nulth healing and actively promote its use. Some individuals explained that they “believe in” traditional medicine but choose not to use it. Others explained they did not know anything about it,

or were perhaps skeptical, and expressed that they would not use it. There was also a range of opinions among community members and NTC nurses as to what degree traditional medicine should be incorporated into the NTC nursing services. Some felt it was appropriate for nurses to take an active role in promoting traditional medicine, while others felt biomedical nursing and “Indian healing” were incompatible or that it would be inappropriate for spiritual practices to be made “mainstream.”

Care as Collective

NTC nursing values represent the family as a client, the whole family, the whole community as a client (Ticma, interview, February 28, 2018).

In pursuing this project, part of the task of investigating care practices and the implications for how patients and relatives are cared for, requires discerning how modes of care diverge in specific contexts and settings of care. Early on in my fieldwork, I was invited to accompany an NTC nurse to a community health fair held in Tsaxana. The health fair was organized in the House of Unity, *Hisumt Maatmaas* (gathering place for people of many tribes), a large and stately building featuring old growth logs and towering weathered totem poles in the entranceway. The space consisted of a large gymnasium-like open space equipped with a kitchen, bleachers, folding tables and chairs, and space for organizing performances or ceremonies. My daughter quickly found a friend and they began to run together in the open areas. On that day, the big house was organized around several information booths on one side, and a section of tables and chairs for resting and socializing along the other. In the morning, many of the young boys sat in a circle to drum and sing. I left my daughter to play with the group of children that were exploring the booths to the right side of the building and sat at the tables where

Elders were gathered, drinking coffee and chatting. I happened to sit beside a friendly fellow, who asked why I was visiting Tsaxana. I talked briefly about my research, and he proceeded to discuss his experience working as a counsellor and shared some cultural knowledge about the Nuuchahnulth calendar and the connection between wellness, seasonal cycles, and the land. One comment that particularly stuck with me was when I described access to culturally safe care as a focus of my project, he simply stated: “cultural safety is today. Having the community together like this, practicing culture.”

Receiving this thoughtful comment early on in my fieldwork aided me to become attuned to something that was repeatedly described as fundamental within Nuuchahnulth communities: the importance of vibrant kin and community relationships for wellness. In fact, in May 2018, I was contracted by the NTC Health Department to complete a systematic review of each of the fourteen Nuuchahnulth First Nations’ community health plans. It was interesting to see how strongly regular community events, cultural groups, and meeting spaces factored into health planning at the community level.

Implicit in the emphasis on community connection as a source of wellness, families play an integral role as the unit through which decisions and responsibilities around care are made. In an interview conducted with Ticcma, an NTC nurse with strong kinship connections to Nuuchahnulth communities, she explained how understanding “the whole family as a client” was integral to her practice. To provide an example, she explained how treatment decisions are made in urgent care situations within the families she frequently cares for:

If it's urgent they're going to make a decision quickly. Sometimes they need time to not just think about it themselves but also talk to other people and part of their family. Because family is so integral, you're not an individual, you're a family, you

know, you're connected to your family, like they're an extension of your body, of your spirit, of your emotions, what one person feels and experiences, so does another person (personal communication, February 18, 2018).

Through Ticcma's description, a sense of wholeness and autonomy in decision-making around care is located not within individuals themselves, but within families collectively. As the body is connected to others through kinship ties, affect and embodied experiences are shared and distributed along these connections.

Ticcma continued by stating, "they're so connected in that way, a lot of the families, and not only that, but they're also connected to the land as well, so there's a lot of sadness and grief around the destruction of land and how things are changing." Connection to land is frequently asserted as important to wellness, as is community and family togetherness in the context of Indigenous health. However, as an "extension of your body" it is not just that connection to community and land are *important* but that disruption to the land or kin is felt simultaneously within the self. In understanding the importance of community gatherings to wellness through Ticcma's description of family connection, social events impact not only individuals as participants in the event, but the collective experience of increased vitality and connectedness reverberates among all present, enhancing and expanding the potential for healing.

Later in our conversation, Ticcma also touched on the implicit nature of grief in caring, when returning to her discussion of the importance of family togetherness in Nuuchah-nulth communities:

So, how important like community and family and friends are. When your people, when your family is killed off to the point of genocide, it's all you have left, is relationships, right? (interview, February 18, 2018).

Ticma had often talked with me about the impact of trauma on the families she cares for as a nurse, often as a result of the colonial legacy within communities, compounded by limited access to health services or discriminatory practices within health care services. However, also implicit in her assertion is the understanding of family as something to turn towards as a source of strength in recovering from loss and grief. In this sense, community vitality is also an act of resistance, where collective acts of care take meaning from a shared colonial reality.

The resourcefulness located in the collective agency of families was a common theme relayed to me. For example, in March 2018, I met with two NTC nurses in Chah Chim Hii Yup Tiic Miss⁴⁸, the Ahousaht health clinic. Over the course of a lengthy conversation, they reflected on this theme through the generosity afforded in the context of a difficult year of loss for the community of Ahousaht.

Hupimin: This past year there was so many funerals, and you know, one right after other. But they were still able to gather together donations of food, donations of money and things like that for the families. And even when so many people might have been on limited income they still managed to contribute in some way or another.

C`a?ak: They had thought, though, that there were no tears left. That they were just, kind of overwhelmed with grief. But you are right, food and money kept flowing.

Hupimin: Mmhm. And there was no question of ‘where are we going to get more?’ So just in the need, there were resources provided somehow.

C`a?ak: Beautiful old teachings about sharing what you have.

Hupimin: I often heard, like when a family has a party, like say a memorial or something, well I was always told to empty my freezer. And they did. They gave

⁴⁸ Ahousaht Holistic Centre: Ahousaht is a Nuuchahnulth community with a population of over 1000 people. It is located on Flores Island, 17.5 nautical kilometers from the town of Tofino.

out all their food at the feast. They prepared it and fed everybody. And you know, just give everything. (interview, March 1, 2018)

Understanding generosity as a valued disposition within families highlights the collective nature of family and community belonging, as acts of care – in this case providing food for families in grief – that are shared and reinforced through the actions of all members of the community. The collective will to “find a way through” difficult times can be understood as an inherent dimension to care within Nuu-chah-nulth communities. Atleo has described a Nuu-chah-nulth philosophy as viewing giving as “natural to creation—in effect, a law of life [...] the interdependence and interrelations of the natural world reflect the interdependence and interrelation of all life forms” (Atleo, 2004, p. 15). This “natural law” extends from symbiosis in the natural world to human social organization. For instance, a Nuu-chah-nulth friend explained to me that it takes six years to prepare for a potlatch, because the hosts will have to prepare to give away everything they have. He also explained that his family was preparing for a potlatch the following year that would be held for all the families in the community who had experienced loss but could not afford to host their own memorial potlatch.

In exploring care as collective in Nuu-chah-nulth communities, there are perhaps two ways of understanding acts of care. Firstly, care may be understood through the lens of social organization and the economy of giving. Care can be analyzed through how neighbours, kin, and professionals are implicated within one another, and how obligations are set or in some cases abandoned (Biehl, 2005; Das, 2015; Han, 2012). Such a perspective may lead one to explore the collective sites of care and their relative import or impact as compared to more individualized forms of care, such as between a doctor

and patient. On the other hand, care as collective can also be understood on an ontological level, exploring the very nature of care, as an event, a potentiality, or a lingering persistence. In understanding care as ontologically collective, as implicating multiple people simultaneously within a shared reality (or at least multiple imbricated realities) it becomes possible to investigate the affective dimensions of care which can have profound and lasting impacts.

At this point, it may be helpful to consider how other scholars have described culturally informed understandings of health associated with various Indigenous world views. Scholars have emphasized the view of health as collective, wherein individual health is imbricated with family, community, and environment and each can mutually affect the health of each of these domains (Anderson, 2000; Downe, 2021; Wilmot, 2018). Naomi Adelson's description of the concept of *miyupimaatisiun* (being alive well) among Whapmagoostui Cree, illustrates how the Cree conception of health "ultimately transcends the individual, and as part of the realm of 'being Cree' is linked to a larger strategy of cultural assertion and resistance" (Adelson, 2000, p. 9). According to Adelson, *miyupimaatisiun*, as a Cree vision of health, is rooted in social identity and relationships to community, history, and the land. Rather than merely describing the absence of disease, *miyupimaatisiun* refers to living in alignment with socially reinforced relationships and ways of being.

Through the Nuu-chah-nulth philosophy of *hishook-ish tsa'walk* (everything is one), spiritual and physical realms of existence are understood as in unity (Atleo, 2004). Atleo retells Nuu-chah-nulth origin stories to analyze how stories contain information about the nature of reality. For example, when Son of Raven captures the day, the

automatic involvement of community reflects community as the natural state of human life. Indeed, Atleo states that “the apparent differences between life forms are real but not in any essential way. Community is a natural order of existence, and one of its functions can be to reconcile the apparent differences perceived among its members” (Atleo, 2004, p. 22). *Hishook-ish tsa’walk*, as describing the nature of reality, implicates the importance of relationships, including unseen/spiritual elements as part of the interconnectedness of reality. Embedded in this worldview are what Atleo terms “relational values.” For instance, the network of relationships defining reality are characterized by the relational values of *isaak* (respect), helpfulness, and generosity. Relational values are pragmatic in the sense that they aligned with “natural laws” of reality (Atleo, 2004). For instance, *hupee-ee-aalth* (be helpful for the common good) does not represent a “humanistic” or abstract moral code but is instead tied to an awareness that the nature of creation holds a collective origin via *hishook-ish tsa’walk*. Atleo emphasizes that relational values are not symbolic but literal and embedded in collective ecologies and the economic strategies applied in coastal communities for over a millennium.

Hinya?agt: Spiritual Awareness

As implicated beings, we live and heal collectively; we care for our relatives, community, and land as an extension of ourselves. In the Nuu-chah-nulth language, *hinya?agt* refers to a state of remaining spiritually aware and *caqaalth* implies that one continues to be supported and connected by their relations⁴⁹. Exploring how *hinya?agt* and *caqaalth*

⁴⁹ Spelling and translation of these terms provided by Chris Seitcher, Tla-o-quiaht First Nation, March 16, 2021.

factor into processes of caring for others reveals the affective and persisting aspects of collective care in Nuu-chah-nulth communities. In an individualistic frame of reference, care is a temporally located exchange between individuals. The individualistic emphasis on care within western biomedicine has been described by Annemarie Mol as the “logic of choice,” wherein patients are constructed as individual consumers who hold the right and responsibility to make informed choices regarding their health (Mol, 2008). This becomes problematic as configuring patients as individuals rather than part of a collective implicates different sets of objectives for health interventions. For instance, how a diabetic monitors their blood sugar and administers insulin has much to do with their occupation, family obligations, living circumstances, and social habits such as eating. Thus, it becomes “hard to disentangle people from their collectives sufficiently for the care they individually need” (Mol, 2008, p. 68). Furthermore, the logic of choice holds individuals themselves as responsible for their choices and resulting health outcomes, thereby negating the relational and affective implications of health care encounters. Instead, what might we learn by acknowledging care as not something bounded within a temporally located encounter, but rather as something that persists? The concepts of *hinya?aq̓t* and *caqaalth* point to the impalpable ways that healing can occur across vast distances through the persistence of spiritual and social connectivity that happens when we think or *care* about someone we know.

To return to the opening vignette of the brushing ceremony with NTC nurses, this event demonstrates the collective social organization of care, as it created a space for the nurses to socialize outside of work. The structure of the event symbolically reinforced a kind of communal sensibility, for example by holding onto a cedar hoop. The instances of

care being practiced within the event can be seen through both the cultural healers' ceremonial acts of cleansing, as well as through each of the participants taking turns playing a role in the sequence. My interpretation of this experience is the creation of a hermeneutic in which individual cleansing and healing was juxtaposed with social connectivity as a mode of healing. Through the imbrication of practices and symbols, incorporeal forms of care had the power to induce – at least for myself – a profound affect of relief.

According to Nuu-chah-nulth knowledge keepers, healing often requires achieving communion with the spiritual realm. Atleo explains that prior to contact, “the Nuu-chah-nulth saw the physical world as a manifestation of the spiritual. More important, for all life forms, the two worlds were experientially one” (Atleo, 2004, p. 10). *Puštaqyuu* (medicine people) could be gifted healing powers through obtaining contact with the spiritual realm through ritual fasting and cleansing (Maquinna George, 2003). This process of communication and travel across spiritual and physical worlds is a key theme in Nuu-chah-nulth origin myths (Atleo, 2004), and is implicated in *oosumich*, a ubiquitous spiritual practice in Nuu-chah-nulth communities.

Oosumich is a way of gaining communion with the spiritual realm, using means such as fasting, cleansing, celibacy, prayer, and isolation. Traditionally, the practice was utilized as preparation for war, hunting or whaling by praying for strength and abilities. *Oosumich* could be conducted for several days to several months, depending on the reverence and strength required for the task at hand (Atleo, 2004). What exactly took place throughout *oosumich* was subject to strict secrecy. Today, *oosumich* most commonly refers to cold water bathing. As described by chief Maquinna George,

oosumich is a “cleansing of the soul, cleansing of the body, cleansing of the mind, cleansing of evil spirits” (Maquinna George, 2003, p. 48). Saasin, a Nuu-chah-nulth artist living in Port Alberni, described *oosumich* as:

For me, it really feels like there's a lot of unspent energy inside of me. And when I go into the cold water, it kind of blasts everything out and it's like really, a really big relief, for my body. And there are maybe different things that I am experiencing but I really believe that the cold water helps my immune system (Personal communication, June 13, 2018).

Oosumich is a highly personalized activity, focused on the relationship between an individual and their sense of spirituality. However, the shape that relationship may take is significantly informed by the guidance of elder relatives.

Towards the end of June 2018, a month after attending the brushing ceremony, I embarked on my first independent trip to visit the northern region. I drove up the highway and turned off at the Zeballos main logging road that was thankfully marked. I was in awe the whole way of the steep mountains, cascading waterfalls, and extensive crags. I had planned on staying at the local Inn at the village of Zeballos for a few days, to attend a community event in Ocleejee, followed by a visit to the Ehattesaht Band office to meet with community members who the Health Director had identified as interested in participating in an interview. I decided to head to Ocleejee, a small community of only about 30 people. At the Nuchatlaht First Nation band office, it was explained to me that there had been a boating accident off the coast of Tofino. Many community members in Ocleejee were travelling to Tofino to assist in the search and rescue and to support the affected families. As a result, the event I had been hoping to join was cancelled.

Figure 9: View of Ehattesaht from Zeballos, June 27, 2018

The following day, I had the opportunity to meet with three women in the Ehattesaht band office. One of the women, Hisʔinwa, shared a moving story about gifts of healing, grief, and the transformational spaces that illness and healing often signify. Hisʔinwa identified as being from Ehattesaht but had lived for many years in Kyuquot with her husband who was a gifted healer and hereditary chief of the Ka:'yu:'k't'h'/Che:k:tles7et'h' First Nations. He also worked as a cultural counsellor for Quu'asa, a program run by the Nuu-chah-nulth Tribal Council. Hisʔinwa explained:

he would travel up to the different nations and helped out where he can. Like even in cleansing out houses and teaching, singing. He was one of the lead singers from our end ... he used to go the rivers and do his *oosumich*, and he used to use Indian

medicines. He was really gifted in different ways. Right from when he was pretty young, he talked about, along with his grandpa, his grandpa was gifted, and he learned a lot from his grandpa. So, he was very well known for different things.

He did a lot of work with young fellows, young men up to our age group, when they were really feeling down, they would call on him, even after hours of work, he was there. People would phone and he'd take their calls and there was so much of that suicide around that there was even people he would take calls like that and he would just talk to them. Or he'd go, if it was up there he would go see them and sit with them and he helped a lot and I had people tell me "your husband was an awesome man" (interview, June 28, 2018).

His?inwa returned to Ehattesaht after her husband passed from terminal cancer.

She discussed how she would like to see *ʔuštaqyuu* (medicine people) as part of the health services offered by the NTC. We stumbled to find the right language to talk about traditional healing. While she used the term "our doctors," she also recognized that "My husband didn't accept that kind of seeing towards him; 'doctor'" (interview, June 28, 2018). Instead, we landed on the term "gifted" to describe the capacity of some individuals to achieve communion with the spiritual world to evoke holistic healing. She continued:

There is a lot of gifted people around. They just don't know it. I know my husband talked about my son, he's my grandson actually but I raised him ... He has a gift and I asked him one time, cause he seen something. We lost one of our young ladies, must be just over thirteen years ago. He was eight months old or something. Or nine months, he was just young when we lost her. And four to five years later, my husband was bringing them to Fair Harbour to go see their dad in Kyuquot, we lived here [in Ehattesaht].

And he was about four or five years old and started talking about that accident, that he was only nine months old when my niece passed. And he started talking about what was happening. I won't say. But he said, but he talked about it. And my husband, he was really shocked. And he looked at our son and he said, what did you just say? And he repeated everything what he said about that accident. And he was really blown away and from that day on, he knew my son had a gift.

But my son, just a couple months ago, I was travelling with him alone, just me and him. And I said "son," I said, "do you remember talking about that accident?" We were passing that site. I said, "do you remember talking about that accident? That happened here." And he looked at me and said "yeah mom, I do." Because he was only four or five and he's fourteen now. And I looked at him and

said "really? You remember everything?" And he said "yeah." I said "wow, son." I said "do you know you have a gift?" He said, "yeah I know I do." I said, "your dad was going to teach you how to use it, but he didn't have that time" [before he passed away]. And he said, "yeah I know." So, like there is people that are gifted. My husband could point them out. He could feel it, sense it. He would say he could sense it.

Megan: It must be tough being sensitive to that stuff and knowing those things, like your son, but then not really knowing what to do. Knowing about the accident would be really tough, I would think.

His?inwa: Yeah. I think they are scared at first, because I know my husband talked at first about how scared he was when he knew he had that gift with his hands. He said he was really scared to try it at first and he would talk to Elders, "that's what I'll try and get my son to do. And he said they would talk to him and just teach him. There are so many different ways he could use it," he said. But you fight off the bad ways and you use it in a good way.

His?inwa's son's gift was revealed through his ability to recount a tragic moment of loss without directly perceiving the event. As a young child, he demonstrated his ability to uncover and bring to the surface a moment which produced deep grief for his family. Guidance is required to help gifted individuals channel their abilities for the good of their communities. However, His?inwa's son lost this key source of guidance due to his father's untimely passing.

Guidance from knowledgeable elder relatives is necessary as spiritual healing can be used to cure, but it may also be used to cause harm or manipulate others (Kelm, 1998; Maquinna George, 2003). As explained by participants, an individual is susceptible to receive both loving or ill wishes from others who are gifted with the ability to heal. One may use their status as a healer to take advantage of others facing vulnerability due to illness or grief. Reflecting the interconnected nature of physical and spiritual realms, illness can also be induced through object intrusion, soul loss and witchcraft (Kelm,

1998). K̓ayuumin, a spiritual healer, described learning to heal object intrusion from her grandmother:

I remember as a little girl, my great grandmother would go to the hospital because doctors couldn't figure out what this guy was going through, [why] he was dying. They said that was the last straw. They called her and she used to always take me to help with her, so I'm learning. And I'm watching him. I am holding this empty mason jar, as a little girl. I'm holding it for her, and she is taking this thing out [of] him. She put it in there and she closed it. I could see it. When you are a little kid, you can see lots, you can see the spirits, the energy. A little child can see a negative person, their energy inside, they don't want to go near them, because then the negative energy of sadness, grief, anger, or even abuser. Kids know. Kids know. So as a little girl I am holding this and I could see what my grandmother put in there. And she went and got my great grandfather [to] put it in the bottom of the ocean way out. That's how serious she took it. So, I seen that. That was at the hospital. The next morning, he was better. And, what they said, they didn't know what was wrong with him, they couldn't figure it out, the doctors. But after her working on it he got better (interview, May 21, 2019).

Though K̓ayuumin did not provide the details on what had caused the object to enter the man's body, she was clear that only a gifted individual could find and therefore remove the object. Both K̓ayuumin and His?inwa belonged to families with a lineage of gifted individuals, in which case the intergenerational continuance of these healing practices was contingent on the guidance of young children by older experienced healers. In this way, care and healing are not only experienced via a collective body, but family cooperation was crucial to the continuance of cultural healing, as a means of dealing with a wide array of ailments from common infections, to psychosomatic depression, to object intrusion.

Mending Fractured Care Networks

The colonial mandate of the Canadian government to assimilate Indigenous peoples through displacement and the eroding of traditional family structures produced the conditions for ill health on multiple levels: through individual experiences of loss, by

disrupting the social body, and by suppressing Indigenous healing. Calvin Morrisseau, an Anishinaabe author, states that colonialism “destroyed the sacred ties that connected our families and communities to one another,” causing pervasive pain and social dysfunction (Morrisseau, 1998, p. 6). Part of the colonial enterprise of cultural assimilation included the suppression of Indigenous healing practices. Many spiritual practices such as the potlatch or sun dance were criminalized under Canadian law up until 1951 (Waldram, Herring, and Young 2006, 149). As a result, there is interest in reviving traditional medicine across Nuuchahnulth territories, but not all communities continue to have members with the specialized knowledge or the socially cultivated gift of healing. For example, Našuk, a woman from Uchucklesaht First Nation, explained that “when I was young, my grandmother taught me about medicine but then I was sent to residential school. I can recognize plants, but I never had the chance to learn to use them” (interview, June 21, 2018).

Processes of colonial assimilation such as the separation of families and the criminalization of ceremony have to some degree displaced Indigenous modes of care (Martin Hill, 2009) and disrupted the intergenerational networks of knowledge transfer (Muller, 2013). At the same time, the introduction of foreign infectious disease and lifestyle changes that predisposed individuals to chronic disease (Kelm, 1998; Waldram et al., 2006) has necessitated new forms of care. In the context where primary health care is not readily available (as described in Chapter 4), there are many individuals living with untreated chronic illnesses. This is a primary concern within the NTC Health Department, yet it presents a variably complex issue. For instance, there are tensions around who should be responsible for caring for elder relatives living on reserve, when younger

family members often travel or move away for employment or are juggling caring for children.

Nunuukma, a young woman living in Ehattesaht, expressed worry that “the Elders don't get taken care of the way that they should be. And that's a little hard to see” (interview, June 28, 2018). She felt that many of the youth in her generation were uninterested in visiting and spending time with Elders, “it’s like they are forgetting the teachings.” When Nunuukma was still living with her now ex-partner, she would help his father and aunt, who were both unable to work. At the time the aunt was going through treatment for breast cancer:

It was a little sad to hear that she had to pay her own family to help her ... Because long ago, it was just family helped you. You didn't even have to ask. But now it’s like you pretty much have to tell them "I'll give you money to help me." It's like another form of neglect, pretty much. Like they were a little shocked that I willingly helped her without accepting the money. Because I helped her out sometimes. But I didn't really expect to get paid the way her family did. It was really hard to see, just because Elders are the most important people (interview, June 28, 2018).

Nunuukma expressed disappointment that her partner’s relatives expected to be paid for providing care to their aunt such as cooking, shopping, and cleaning, and assisting with her medications and appointments.

The discussion of relatives “getting paid” to provide care is linked to the Care Aid program, a crucial service in remote Indigenous communities. Care Aids are trained home care workers who live in-community and are employed by the First Nation to provide cooking, cleaning, and other basic care services to community members with complex health needs. Care Aids work in concert with the NTC Home Care Nurses, who develop care plans for the Care Aids to meet the needs of clients while the nurses are not

in the communities. In small villages, it is often a close relative or neighbour who takes on the care role. Policy supporting the Care Aid program has shifted in recent years to require specific certification. Unfortunately, many of the students who travel away from home to attend training continue to work in urban settings, leading to a concerning dearth of care aids on reserve. A woman from Dítidaht First Nation remarked that there are several women in her community willing and able to work as homemakers, but the band would not employ them because of a lack of certification. One of these women had been working as a Care Aid for a decade prior to the change in policy. This situation points to a broader shift from dependence on family and community care networks to institutional models such as professional home care or moving away from home to live in an urban nursing home.

Nunuukma experienced this as a failure to live up to Nuu-chah-nulth norms. However, the current socio-material context often does not allow for more traditional structures of care. C'aʔak, an NTC Home Care nurse working in the central region, explained that:

The biggest work in keeping someone [elderly or with complex health needs] at home is the family support. Our, we have a great home support program funded by FNHA with personal home care workers, homemakers in people's homes. But all they do is support the family in taking care of someone that needs help at home. There is no full-time kind of support. Weekend, evening, night. It's just a daytime kind of support. So, the really big work for anyone keeping Elders at home, lies with the family. And it's an old kind of cultural thing that we keep our family at home but the whole social dynamic has changed, and women are all working so we used to be able to help each other out and share children and share meals and share taking care of our mothers has all shifted because we are all working. And that's not just a time commitment. It's an energy commitment. So, it's a whole, huge change since the '70s, I was thinking that. But the expectation is still there that we take care of our families. So, it's hard (interview, March 1, 2018).

C`a?ak explained that socio-economic shifts have made it difficult to sustain the traditional village networks that collectively supported care for Elders and children. Compounded with this, the lack of access to primary health care on reserve means that chronic diseases, such as high blood pressure or Type II diabetes, which could be managed by a family physician, are left untreated, often until symptoms become much more serious. The disruption of traditional care networks has catalyzed another demographic shift. In this case, elder relatives are increasingly being moved away from home where they can receive around the clock care in urban nursing homes.

In order to keep elders at home, support is required to ensure daily medications are taken appropriately, and assistance with travel and shopping (where it is necessary to leave the community for groceries, prescriptions, or appointments). Additionally, timely housing repairs are required to prevent falls. Currently, elders with complex health concerns choosing to continue to live at home face significant risk. Hasp`iqak, a Nuuchah-nulth health leader, added that:

... And possibly another barrier is that if you have somebody who's at end of life, and you want to have your family with you, they [medical travel assistance] won't cover the whole family generally, right? On the other hand, though too, they are getting better in the North Island hospitals with having a large room and having more than one or two visitors for First Nations people. And they did also put in gathering rooms for First Nations people who wanted to access that.

Megan: Do people generally prefer to go through the end-of-life process in the community?

Hasp`iqak: I think they would prefer it, but it's just not always able to. There are some things I guess that nurses aren't able to administer. And because there is no twenty-four-hour doctor support here. And sometimes you don't realize it. Sometimes people don't realize that whatever their ailment was that they're thinking is "they will just give me a couple of pills and I will be fine." But if it's progressive, fast working cancer so they are out and going through, if they've

agreed to go through some of the therapies and things like that, they don't always know that it's their end of life (interview, March 15, 2018).

As Hasp'iqak explained, there are barriers to having family to come together for a terminally ill loved one, once they are moved out of community. Yet, there are incredible challenges to keeping them at home as well.

To return to the concerns that youth were “forgetting the teachings” about caring for relatives, it seems instead that external and systemic pressures that produce health inequities (as described in Chapters 4-5) are what lead to the devastating lack of primary care and culturally safe care options in Nuu-chah-nulth communities, not a lack of willingness among the youth. In Chapter 4, I introduced the story of ʔiihmisuk, an Elder in Kyuquot, who lived in fear because of her health status, yet was surrounded by loving relatives. ʔiihmisuk's story, and stories like hers, point to the persisting experience of abandonment from crucial public services that co-exists alongside profound relational forms of care that simultaneously challenge, enhance, and are marginalized by biopolitical standards of care.

Relational, collective, and spiritually attuned modes of care are enacted in the context of health inequity and the legacy of colonial violence. In this way, informal relational care offers a powerful space or catalyst for cultural resurgence and challenging or mitigating health inequity. It holds the potential to mend fractures in the social body. Ontologies of care as collective, premised on *hinyaʔaqt* and *caqaalth*, offer a powerful means of mitigating the health inequities stemming from settler colonial processes and a biopolitics premised on exclusion and systemic racism. For instance, when family is “an extension of your body, of your spirit, of your emotions,” then collective healing

practices reverberate and expand the affects of release, hope, and comfort such as was experienced during the brushing ceremony or Tsaxana health fair.

Related to this, in experiencing care as a connection rather than a discrete act, care implicates a constant potentiality for immense grief. Settler colonialism has historically been and continues to be a harbinger of grief for colonized peoples. I find confronting grief a necessary task of unmasking the roots of racialized health inequity. To do so also requires finding a means to attend to grief in a way that does not objectify suffering. I believe these means can be found within the Nuu-chah-nulth language. A friend of mine from Tla-o-qui-aht First Nation translated the phrase *yaʔakuk^{wah} suw'a* (I love you) as “it pains me when you are away.” Similarly, Richard Atleo explains that “the world for love, *yaw-uk-miss*, includes the experience of pain. The Nuu-chah-nulth experience over millennia has found the goodness of love to be inseparable from the experience of pain” (Atleo, 2004, p. 15). *Yaw-uk-miss* demonstrates a duality inherent in love, where the great joy and warmth that comes with loving another, is always complemented with the vulnerability of the depths of pain that comes with losing someone we love.

Though many Nuu-chah-nulth-aht consider themselves as presently part of a “grieving nation,” there are responses to grief embedded in *hahuupa* (traditional teachings). These teachings enable families to live alongside loss with reverence. For example, many follow the practice of changing one’s name to the name of a recently passed relative for the duration of a year, as a form of memorial. Offices close and events are cancelled to mark the passing of community members. Cedar boughs may be laid down along the roads travelled by the recently deceased on route to their resting place and complex memorial potlatches are organized in honour of their memory.

On my last day at the NTC head office, I was chatting with a few nurses in one of the offices. One of the nurses turned to a picture of an Elder that had been given out at a recent memorial. There was a discussion about what to do with something of that nature. A nurse who had been married into one of the communities for many years explained, “you keep it out for a specific number of days, and then you put it away in a safe place for a year. Four years for a chief.” The nurse who the photograph belonged to, relatively new to the profession, lamented that it was their first client to have passed away. They seemed comforted by the fact that there was a protocol in place for this kind of thing.

In each of these ways, Nuu-chah-nulth language, teachings, and practices provide the means for attending to grief, bringing it into our homes and even our personal identities to honour those we *yaw-uk-miss*, or pain to have lost. Allowing space for grief enunciates the enduring capacity of love. Settler colonialism has worked to suppress Nuu-chah-nulth healing practices through both direct and indirect mechanisms. Directly, healing practices were outlawed and families were separated. Indirectly, health disparities are experienced through the untimely loss of loved ones or through the burden of intergenerational trauma. However, despite these impositions and loss, the persistence of relational modes of care – that construct care as something that persists and can be embellished through communion with the spiritual realm - offers a way of responding to and healing from loss.

***Caqaalth*: Social Connectedness**

Attending to grief is a way of caring for both ourselves and for those we have lost, which can have ramifications for emotional, spiritual, and physical health, as well as for the health of the family and communities connected to the person we have lost. Attending to

grief highlights how care can be more than the practical things we do to improve quality of life for others, such as washing, feeding, performing an examination, giving an injection, or making a diagnosis. Beyond this, care can also imply or produce *caqaalth*, the persisting state of being supported and connected. When care is collective, the connections formed with those we care for, those we are together-with in the world, do not dissipate proceeding the encounter. They are not temporally limited. During the Nuuchah-nulth Patient Voices project, K̓ayuumin, a spiritual healer, shared a profound story during her interview about how she came to be surreptitiously invited to do cultural healing in the local hospital. The story reflects on her role as a cultural healer as an ability to be “called to by the minds” of those she has cared for. She explained an example where:

There was this lady, I had never met her in my life. The nurse called me to come up to go see her. I walk in there and she was in a wheelchair, but she was in the bed. They said she hadn't eaten for two weeks. She was giving up. I walked in there and her whole room, you could just feel it. When I walk into a room you could just feel the energy, the spirits in there, the energy of the person, and the comfort, just like when I walked in here. But when I walked into her room, it was all grey and she was all grey. The aura colour was all grey. She was determined to pass away, determined to die. She was in a wheelchair for some time now. I went in there and I did my cultural part.

... So, I continued and then, about a half-hour, hour later, I finished my cultural part and the ceremony, the healing. And then, the lady in the bed says, "I'm hungry." So we buzzed for the nurse. And I said, "she's hungry." And the nurse was just, like, almost crying. It was, again, she had no will to live and I helped her with that moment.

And it was years later, she would call me through her mind. She had no phone sometimes, wherever she lived. But I always ran into her. Of all places, one time I ran into her in Tofino. She said, "oh you heard me! I was calling you." A lot of people say that to me, "I was calling you," through their mind. And I ran into her. She said, "I was calling you." She lived for a number of years. She ended up losing one leg, and then she still continued encouraging others to carry on. I'll never forget that. I was pretty young! I was really young, so I was like, woah! It was awesome to see her be able to change from that. And it was my belief between the

creator and her, and the cultural healing, the singing, the rattles. Everything I use. (interview, May 21, 2019).

Through the use of singing, rattles, spiritual connection—and likely other activities that were not disclosed to me⁵⁰—Ķayuumin was able to help the woman overcome her emotional struggles and the physiological challenges she experienced as part of the condition that prevented her from walking. The healing that was effectuated between the woman, Ķayuumin, and the creator (as Ķayuumin explained), was a caring connection that remained meaningful and tangible for both these women throughout their lives, even at times when they were unable to physically communicate with one another.

An important aspect of spiritual healing involves supporting others to set aspirations, hopes, and dreams as a precondition for healing to take place. Ķayuumin illustrated this through another story, where nurses had called her to the hospital to help with a patient who had been admitted for attempted suicide. Because the woman was to be discharged the next day, Ķayuumin offered to pick her up from the hospital and drive her to her home. She explained:

I was sitting there, learning more about what happened prior to that last attempt. And realizing, and she felt comfortable with the cultural part, I ended up spending all day with her. All day ... I worked with her. Spiritual healing, cleansing. Then I had also talked about how she was where she was and what she would like, her dreams, and I helped her with that culturally. And then her, herself. And how she learned how she can empower herself with tools of cultural.

And she never ever went back. The suicide attempts stopped. And the nurse said, "what did you do?" I happened to run into her months later. She said, "what

⁵⁰ There is a large degree of secrecy associated with traditional healing in Nuu-chah-nulth communities. This was explained to me as both a way to preserve the efficacy and potency of traditional healing, as well as because healing, like prayer, is a private, personal endeavour. In acknowledging the secrecy and sacredness of traditional medicine, I generally avoided probing for additional details about the specific practices undertaken and allowed contributors to determine what elements of healing practices were appropriate to share and what was to remain hidden.

did you do with her? We haven't seen her." And I said, "that's between me, her and the creator."

It was two years after I ran into her [the patient]. She moved to Victoria. She got a job. She dressed totally different ... She was happy. And it was like 6 years later after that she ended up having a heart attack. And even though I didn't see her far in between, it was like I kind of grew fond of her, even though, because I knew she was happy. She was going to be able to live. And I just said to myself, that wasn't the way she was supposed to pass away, suicide. She had a chance to be able to live. That's my key, is somebody to be able to live (interview, May 21, 2019).

This story illustrates how connecting with others with the intention to create hopes and dreams offers a powerful mode of care. K̓ayuumin assisted the woman to become more *hinya?aq̓t* (spiritually aware) and to feel *caqaalth* (socially connected and supported) which ultimately transformed the woman's sense of hopelessness into contentment, which enabled her to "be able to live."

This insight was reminiscent of Indigenous teachings that the intentions we hold while we make or do things for others can be in some way received or consumed by a recipient. During my master's research, a Cowichan medicine woman explained to me that "sometimes people say they can hear my singing when they open the medicine" (Muller, 2013). Through an ontology of care that is collective, the acts and objects we perform and produce with care for others are both embedded in the relationship, while also transcending the physical act of care. In a way, intentions become entities in their own right through care practices, which both healer or caregiver and recipient may draw on as a source of strength.

In speaking with NTC nurses, it became apparent that there were modes of care that produced *caqaalth*, which have been formalized and integrated within the NTC nursing practice. For instance, "The Mother's Story" is an integral intervention practiced through NTC Community Health Nursing which empowers expectant mothers to design

their own care plans with the support of nurses. This intervention was designed in partnership with Nuu-chah-nulth Elders and families and emphasizes focusing on the client's perspective on quality of life. The nurses use motivational interviewing techniques to invite conversation with clients, allowing them to share about their health and expectations for their pregnancy on their own terms. These motivational interviews elicit a range of health descriptors centered in the client and family's experiences, perspectives, values, beliefs and goals which then guide the care provided by nurses. Nurses record and chart these conversations in specially designed qualitative pre-natal assessment forms in the clients own words. The discussion around hopes and dreams is a pivotal aspect of the intervention. The nurse then works with the mother and her story to engage in goal setting. Revisiting the story and identified goals offers an opportunity to support and encourage families when faced with personal challenges.

NTC nurses expressed that they felt this approach was an important complement to existing medical records. ʔišmąpt, an NTC Community Health Nurse, explained that “it gives me a real perspective of how that birth went for them. I have all the medical papers; I have all what happened during the birth. But it's different than their personal perspective. So that gives me a little window into what supports they might need” (interview, December 14, 2017). For example, the Mother's Story documentation may help nurses to assess risk for postpartum depression or anticipate possible complications with breastfeeding. According to the nurses, “lived experience can be really powerful,” as it can reveal why someone may accept treatments or not or it can remind people of their hopes and goals when they are struggling.

Kakawin, a Nuu-chah-nulth Elder and key voice in shaping the NTC Nursing Framework, shared some thoughts on the Mother's Story program during a conversation over tea in the kitchen of my basement apartment in Port Alberni.

Some nurses were uncomfortable asking the mothers their story. With my daughter, the nurse just gave her the sheet [of paper] and it made my daughter uncomfortable. She said, "I'm not sure how to answer this." I said, "the nurse wasn't supposed to give it to you, she was supposed to help you figure it out." So, when she was burying the placenta⁵¹, she realized what it was. For example, she wanted her son to be good with computers, like his father. It's about your hopes and dreams, what you want for the child. When she was doing that, she realized what her hopes and dreams were. (Notes taken during personal conversation, August 28, 2018).

In this story, Kakawin's daughter initially didn't see the value in the Mother's Story approach, when she was asked on the spot to identify her goals for her pregnancy. However, in other instances, clients and nurses found the conversational process of identifying hopes and dreams as empowering and offering a possibility to identify new and often unexpected opportunities for expectant mothers to "turn around the intergenerational impacts of trauma" (Smith et al., 2006) and set aspirations for themselves and their growing families. Through relational approaches to nursing (such as the Mother's Story program) or participation in ceremony (the burying of the placenta), the collaborative creation of hopes and dreams offers a mode of care with lasting impacts for mothers, families, and young children.

⁵¹ Burying the placenta was identified to me by a number of individuals as a common cultural practice within Nuu-chah-nulth communities. The placenta is buried along with symbols that identify hopes and aspirations the family holds for the baby's "pathway" in life.

Conclusion

In any given health care encounter or illness experience, one is likely to confront multiple co-existing ontologies of care. These overlapping ontologies compete for explanatory or therapeutic power, and have material, affective, and moral dimensions. In some instances, diverse ontologies of care work together to produce more hybridized practices. It would be possible to describe the NTC Nursing approach as a hybridization between biomedical nursing and Indigenous approaches to healing. Yet the NTC nursing practices are simultaneously caught between competing pressures and obligations that are reflective of the broader conflictual relations between Indigenous Peoples and the Canadian state (which I take up in Chapter 7). Furthermore, there is a persistent structure of feeling (Williams, 1961) that characterizes informal care in Nuuchahnulth communities, which challenge and expand dominant approaches to care in health care contexts. This structure of feeling is informed by ontologies of healing and their corresponding affects and morality, such as *hinyaʔaqt* (spiritual awareness), or how the gift of healing abilities is cultivated spiritually and socially. I have also touched on ontologies of care, such as *caqaalth*, the persistent connection and support that becomes material through acts of care. A similar thread between these ontologies of healing and care is the collective nature of human striving towards health, recovery, or wellbeing. They are fragments of or compositional to a relational ontology. They point to our implicated nature, where joining together becomes a form of healing, and where family and the land are an extension of the self.

These ontologies are not unitary or uniform but are evoked through care practices. Rather than implicating sameness among those who share similar ontologies of care, they

reinforce individual creativity as families form care decisions in response to traditional teachings, contemporary circumstances, and “making do with whatever is on hand” to ensure loved ones’ health needs are reasonably met. All this occurs in a context where colonial assimilation policies have separated families, the imposition of biomedicine has displaced spiritual and emotional dimensions of healing, and the increasing need for professionalized care continues to shift family dynamics. These ontologies of care offer powerful responses to mitigating some of the damaging effects of colonialism, while at the same time they continue to be marginalized by dominant care models. In this way, to care can evoke powerful affective states and is potentially a source of transformation. This seems obvious on an individual level if we reflect on our own experiences of health care providers who may have helped us to find the right medication or start to feel “normal” again after illness or injury. But where ontologies of care are collective, it offers a source of social transformation (a theme I will return to in Chapter 7).

Significantly, ontologies of care as collective expand conventional biomedical understandings of care in the sense that they bring attention to the healing that occurs through acts of care which persists long after the care encounter itself. After someone walks away from a medical appointment, the affects produced in the encounter persist, in much the same way the connections formed through spiritually informed acts of care persist through the ability to “call someone with their mind.” As evidenced in many of the stories and anecdotes shared with me, ontologies of care as collective implicate multiple people simultaneously, and not just the immediate individuals providing or receiving care, but many people as part of a whole which is the family or community. In reflecting on how this might translate into institutional sites of care, I am reminded of an

ongoing debate in the region around the importance for Indigenous patients of having families present when relatives enter the hospital. Despite incremental changes in visitation policies and available public gathering spaces in hospitals, ongoing frustration persists around how the healthcare system only ever acknowledges these pleas on a surface level, without any systemic integration of advocates and family members into the process of care and decision-making around treatment and discharge.

Recognizing multiple ontologies of care and situating them within broader colonial relations elucidates what is truly at stake in the argument over families visiting in hospital. It is possible that these patients and their families have had to travel significant distances. Relatives, as implicated with the patient, suffer alongside and heal alongside and through the health crisis one individual may be enduring. As Našuk, a Uchucklesaht Elder explained, “it is very important for family members to be all around and talking to one another when in the hospital. They offer the love, support, and feeling wanted, and encourage to fight hard to live. The hospital is bad for not supporting this. That’s what we do, we all gather” (Interview, June 21, 2018). We might also recognize this sentiment in the colonial history of the forced removal and racial segregation that occurred through the residential school system and Indian hospitals. Another implication for care as collective is a deeper recognition for what happens in the inverse of healing occurring through “families getting together,” that is the breaking apart of families and the collective ramifications experienced as historical trauma.

The values and experiences that were emphasized to me around what it is to be a member of a Nuu-chah-nulth community, such as community gathering as healing, the whole family as clients from an Indigenous nursing approach, and generosity as a source

of resilience, offers insight into how Nuuchahnulth people experience health care encounters and some of the ways the system fails to meet an acceptable standard of care (such as excluding family participation from decision-making). By ignoring the affective dimensions of different modes of care, it is easy to trivialize the encounter between patients and healers as one based on particular sentimentalities that some patients may prefer over other approaches. Or, in guidelines-based care, one might also trivialize such an approach as one to be added to a checklist and otherwise discarded. In contrast, by highlighting the affective dimensions of care, my aim is that this chapter is a beginning toward suggesting the profound ways these encounters may be taken up in people's lives and persist throughout their lived experiences as something to return to in a difficult time (like the Mother's Story charting), or to call upon through our minds (such as the relationship between spiritual healers and patients). Such encounters may continually inform relationships and relational accountabilities in how people orient themselves to one another, to family, to community, to land, and to the cosmos, especially in terms of finding strength in times of grief.

Chapter 7: “Renovating one Room in the House at a Time”

Towards the end of my fieldwork, I was working in the NTC Office on a sunny and hot day in May. It was a typical day in most respects, except that I had stopped to take note of the general atmosphere that surrounded me. When I came into the department that morning, I commented on how high the energy level was, with people moving around and talking excitedly. From my office I could hear multiple phone conversations going on. Across the hall, the nurse navigator was discussing how to improve the All Nations meeting room at the hospital using community feedback. The objective of the meeting room was to allow family to be present to support their loved ones while in hospital. “... just the importance of how it [family] is medicine ...” farther down the hall I heard the nursing manager on speaker phone with what sounded like a bunch of professional older men (I assumed doctors or health administrators) strategizing how to increase access to physician services in the remote communities. I had just gotten off the phone with the Executive Director of a health clinic about hosting a lunch with their physicians to discuss participating in the Nuuchahnulth Patient Voices project. Through these examples and countless others, the NTC Health Department provides a hub for health advocacy and development.

In this chapter, I return to the ways that the *Hupiimin Wiikṣah̓iiy’ap* (helping us to be well) Nursing Services have redefined care by practicing a relational approach to health care, which has improved both quality of care and access to health services in Nuuchahnulth communities. I am interested here in the imbrication of health and

politics by revisiting the connection between self-determination or nation-rebuilding and health care. I have demonstrated in previous chapters how Indigenous healing produces alternative local moral worlds through enacting relational and collective ontologies of care. Yet, a settler colonial biopolitics continues to circumscribe and marginalize Indigenous healing. In practical terms, this produces a tension between the health needs as asserted by Nuuchahnulth communities, the scope of practice available for NTC nurses to maneuver through, and the specific sites of care where these do or do not coincide. There are simultaneous, oppositional movements between enacting new local moral worlds that reframe care, even in biomedical contexts, and the colonial legacy linked to systemic racism that oppresses Indigenous ways of knowing and excludes Indigenous peoples from accessing health services.

However, these contradictory and co-occurring movements are framed very differently, depending on the position from which one might analyze the situation. Reviews of recent policy changes in Aboriginal Health in British Columbia tend to paint a promising picture of a novel approach to health governance. For instance, the *Transformative Change Accord* (2005) has been described as shaping public perceptions and “Indigenizing Canada’s political discourse” (Wilmot, 2018). Prior to the Transformative Change Accord (TCA), there were no comprehensive policy regarding how regional authorities should engage with Aboriginal communities in coordinating services (Lavoie et al., 2015). This issue was identified in a series of agreements known as the *Kelowna Accord* (2005), which sought to address relationships between provincial and federal governments and Indigenous peoples in Canada (Wilmot, 2018). These commitments influenced the emergence of new healthcare bodies in BC, including the

First Nations Health Council (FNHC, representing First Nations in the health regions of BC), and the First Nations Health Directors Association (FNHDA), which led to the creation of the TCA that same year (Government of Canada, 2005b).

The approach outlined in the TCA is to re-establish relationships between First Nations and the British Columbian government based in principals of recognition and respect as the basis for eradicating social and economic disparity (Lavoie et al., 2015). A *Tripartite Agreement-in-Principle* (2011) was also signed between the FNHC, FNHDA, the federal government, and Province of BC, which established the First Nations Health Authority (FNHA) as a province-wide healthcare provider in 2013. Although the FNHA's constituency is province-wide, it operates on par with the regional health authorities under the direction of the Ministry of Health, in a provider rather than political function (Wilmot, 2018). Through the creation of the FNHA, the federal jurisdiction over Aboriginal health services formally held by the First Nations and Inuit Health Branch – Pacific Region (FNIHB), which includes the planning, managing, delivery and funding of various health services was shifted to a provincial body representing the interests of Indigenous communities in British Columbia (First Nations Health Authority, 2017).

This shift in policy direction has been widely celebrated as being “of fundamental importance to improving the health inequities faced by Indigenous people in Canada” (Allan & Smylie, 2015, p. 31). Since its inauguration, the FNHA has committed to “embed cultural safety and humility into the health care system ... The ultimate goal is a future where First Nations peoples have a new relationship with their care providers based on mutual respect, understanding and reciprocal accountability” (First Nations Health Authority, 2019, p. 68). At the time of writing, the FNHA is engaged in numerous

education and advocacy efforts, and the push for cultural safety and humility in sectors of the health system, and this has had a profound influence. For example, Island Health, the regional health authority serving Vancouver Island, is developing a cultural safety strategy, has implemented cultural safety committees in many BC hospitals, and is increasing the hiring of cultural safety coordinators. These committees and coordinators give voice to the experiences of First Nations patients, implement action plans to improve patient experiences, and elicit input for traditional wellness plans. NTC nurses also noted changes since the creation of the FNHA. NTC nurses suggested that the FNHA was responsive to “how to help people going through trauma,” had incorporated a more holistic focus, involved Elders and knowledge keepers in health planning, and made more effort to connect with Indigenous communities.

These newly constructed spaces created to attend to the relationship between state governance over health care and Indigenous communities offer an opportunity to “transform the terms of discussion of First Nations health matters, using cross-boundary links to promote First Nations principles, terminology, and political traditions” (Wilmot, 2018, p. 5). However, a more complicated picture is revealed when juxtaposing these “transformations” to the experiences of health leaders working in a tribal council that has been advocating for self-determination for decades, or to the experiences of Nuuchahnulth-aht who remain skeptical that any substantial changes to access or to the quality of services available actually address their health needs.

These recent health policy and service structures have been described as “policies of recognition,” developing a “targeted parallel” health care system, “as a system that targets the needs of a particular minority by substituting focused services for mainstream

ones” (Wilmot, 2018, p. 3). However, I find the claim that a parallel health system is a means of targeting the specific needs of Indigenous communities misleading, as a parallel system has always existed in Canada and has historically contributed to disparities in health (Meijer Drees, 2013; Waldram et al., 2006). Interestingly, during my time at the NTC, I had on a few occasions heard criticisms that the FNHA was just a “rebranding of Health Canada” that in many ways continued to undermine the control and influence of the NTC.

I find Athabaskan scholar Diane Million provides an apt description of the current political moment as a “time of great contradiction” where spaces for self-definition open up at the same time they are constrained (Million, 2013). In response, this chapter explores how to theorize transformation and persisting oppression as co-occurring simultaneously – the shifting social dynamics that enable historically marginalized moral worlds to take precedence in health legislation, at the same time they are limited and circumscribed by that same process. I also draw from the work of Elizabeth Povinelli, which explores the persistence of alternative social projects by “conceptualizing ... neoliberalism as a series of struggles across uneven social terrain [that] allows us to see how these heterogeneous spaces provide the conditions for new forms of sociality” (Povinelli, 2011, p. 17).

The modes of care sketched out in this thesis must be understood as responding to and in tension with historical and ongoing colonization in Western Canada. The relational approach to care provision enacted between Nuuchahnulth community members and NTC nurses exemplifies a resistance to institutionalized forms of health care that have historically been linked to processes of colonial domination. Yet these modes of care

must also be understood as having their own lineage as well as holding relevance for how we understand healthcare broadly.

In this chapter I address the tensions between the ideal of self-determination and relational care, how it is taken up in current policy frameworks, and how “mainstream” medicine is both profoundly influenced by and resistant to Indigenous healing and alternative modes of care. In doing so, I argue that what is at stake is not contradicting definitions of health, but rather the coexistence of multiple ontologies of care which inform disparate ethical orientations and obligations. I draw on the comparisons made by NTC nurses between the “task-oriented” nature of “mainstream medicine” versus the relational approach of “simply knocking on doors”. I then connect this to the politics of cultural recognition in late liberalism, highlighting the link between biomedical models of reality and colonial governance structures. I argue here that liberal recognition is structured to offer symbolic but not material or substantive redistribution of power between Indigenous Peoples and settler states. To support this stance, I draw on two case studies, the Health Transfer Policy and cultural safety policy, to flesh out the relation between colonial governance and a persistent tension between the health needs expressed by Indigenous communities and what is made materially possible through incremental changes in Aboriginal health policy. Lastly, I contemplate what this means for self-determination over health care and the possibility for transforming relationships between Indigenous Peoples and health care as an apparatus of colonial governance. By using the metaphor of “renovating one room in the house at a time”, I show how the indeterminacy of biomedicine and liberal recognition enable the persistence of alternative social

projects, not only to simply endure, but to assert influence by shaping conversations on the ethics of care.

“Getting to the Task” of Care

We’re encouraged to take time with our clients. For immunizations, I don’t have a set half an hour to do immunizations. I can take an hour if I want to. Because we find different things come up during immunizations and it might take a bit longer. That’s what I love about it [working at the NTC], it’s just... If I’m only going to see four clients a day, that’s ok. We probably did a lot of work with those four clients (interview, NTC Home Care Nurse, December 14, 2017).

The most discussed contrast between “mainstream” nursing and the NTC approach was what nurses referred to as a “task-oriented” approach. Nurses explained that outside of the NTC nursing services, health care providers are constantly under pressure to complete various tasks with limited time available to complete them. Many NTC nurses found it challenging to operate outside of the task-oriented approach when they began nursing with the NTC. Žišmapt stated that when she started:

I was again very task orientated, “I gotta do this blood pressure, I gotta do this, I gotta do that.” It was like I get to sit here and have tea. It was kind of hard to, I guess to chill, relax and take a breath. And just be present (interview, December 14, 2017).

A common experience shared by NTC nurses was learning to appreciate that by just “being present” they were accomplishing “a lot of work” in terms of supporting clients to manage chronic illness, assist with diabetic foot pain or get up to date on their immunizations, to provide a few examples. Additionally, NTC nurses commented on how relational care requires a significant time investment to build rapport with communities and clients.

According to Ǵay’ama Nuči, “it takes two years to learn your way around”. She explained that:

[NTC management] still wants that kind of data but they also want you to build a relationship. Which is almost counter to getting the data, getting the task. Because the relationship building is a whole different ball game. Out of that we still have to get the task done, for the reports. So, it's like, you're conflicted all the time. You know what you have to do as far as relationship building. But that means sometimes you don't get *the task*. You get to the task, because that's why we are there, we are there to do things. But sometimes it takes longer to get to the task (interview, March 28, 2018).

Ŷay'ama Nuči's comment reflects the different ways that priorities are organized through different ontologies of health and care. Often taking a relational approach means that nurses are unable to "get to the (clinical) task" immediately. But if cultural safety requires transferring control over a healthcare encounter towards patients, then arriving with a pre-determined task become antithetical to the prospect of culturally safe care. Because nurses must report to management, and management must report to funding bodies such as the FNHA, "accomplishing tasks" lingers as a pressing priority which NTC nurses must carefully navigate in their dealings with patients.

What is interesting about the contrast between being "task-oriented" and relational nursing is the way that care is being evaluated; in conventional nursing, job performance is tied to the number of clients seen throughout the day, whereas in a relational approach, it is the quality of time spent with clients that is most valued. Because of the task-oriented focus in conventional health care settings, nurses and physicians don't have much time to spend with patients, nor opportunities to explain diagnosis and treatment. This lack of communication is frustrating for many Nuuchahnulth families, and NTC nurses actively work to fill this gap by spending time to discuss and explain recent diagnosis and care plans with clients. NTC nurses described this role of "translating" as key to their role as a nurse.

Within the home care and community health nursing provided by the regional health authority, patients are contacted three times before their case is closed for failing to respond. These individuals must obtain a new referral from a doctor if they wish to pursue receiving nursing care. In contrast, the NTC maintains a database of clients that nurses check in on. Clients who are not immediately responding are not removed from the list. Ticcma, an NTC Home Care Nurse, explained that “some patients are one step forward, three steps back. You have to understand what they are going through to understand their health behaviors. A lot of the time it is emotional healing that has to happen before they can make any changes towards a healthier lifestyle” (personal communication, n.d.). Through a relational worldview, addressing one particular health concern (e.g., managing diabetic glucose levels) may require multiple layers of healing (e.g., coming to terms with a recent family loss) that medication alone cannot address. This requires coming to care *about* patients, rather than for patients, by gaining understanding about their lived experience (Woods, 2012).

Y’am’a, an NTC Home Care nurse explained that in “conventional” nursing, nurses are advised not to become attached to patients, as emotional investment is viewed as damaging towards professional rapport. She explained:

I was always taught at nursing school you don’t get attached. These are your patients, don’t become emotionally attached. But now [at the NTC] we are at the completely opposite end of the spectrum where that is part of our job is to be attached and to be connected. And to understand and to know and to listen and all of that (interview, December 7, 2017).

Similarly, several nurses described the NTC nursing approach as humanizing; “It is a profound humanistic approach from the ground up” (interview, March 28, 2018).

λusmit, an NTC Home Care Nurse, explained that a relational approach is necessary to providing nursing care in the context of pervasive grief:

There might just be something more pressing. Like this morning, when I was over visiting, you know, this man has a lot of health concerns, but his main concern today was all the losses he's had recently. Like his sister died, and his uncle died. So, it was more talking about grief and loss, cause that's what was important today (interview, February 8, 2018).

These examples, including client lists, embracing emotional investment, and knocking on doors, reveal how different ontologies of care materialize through sets of practice and distinct ways of attending to patients.

Part of building connections with patients requires working outside of scheduled appointments and actively checking in on them. In Nuu-chah-nulth communities, a routine nursing practice is to knock on doors around the community. In some cases, the NTC nurses are invited in to provide care and check up on case histories that they have been following. Sometimes they are welcomed in for a visit, but do not “accomplish” anything in a “strictly medical” sense. NTC nurses explained that sometimes what a client can benefit most from is a supportive conversation. In other cases, the nurses are unable to get in touch with the clients or the client may refuse care. Regardless, there is an expectation within the communities that the nurses will come and check up on individuals who are known to be in need of health services by making a phone call or knocking on their doors.

Taking time, being available, and making the effort to connect with the communities has been crucial to increasing access to health services and reducing health inequities. An NTC Community Health Nurse reflected on supporting clients through times of crisis:

The one family that I've been working with quite closely for a year, more than year, I mean I certainly think it's been extremely supportive for them. They're just a

young, high-risk family, and, you know for months and months on end I saw them once a week. I think that support was really important. To help to carry the situation through MCFD [Ministry of Child and Family Development] surveillance and to move through that and out of it. So hopefully just allowed the experience of feeling supported, for that there was someone on her team, on their team (personal communication, March 28, 2018).

In her role as a Community Health Nurse, she was able to connect with the family to “accomplish tasks” such as providing immunizations and maternal and child health. But at the same time, she was able to do much more. Through her supportive relationship with the family, she was also an advocate with the position to influence MCFD interventions. The support and advocacy in turn influenced the family’s journey towards raising healthy children and emerging from the risk of state-imposed child apprehension.

The “task-oriented” mentality has been a subject of focus for medical anthropology through a critical interrogation of materialistic and reductionistic tendencies within biomedicine. Kleinman and van der Geest explain that the emotional and technical/practical dimensions of care have increasingly become separated in biomedicine (Kleinman and van der Geest 2009). The narrow focus on the technical aspects of care presents a “kind of radically materialist thinking [which] is the product of a Western epistemology extending as far back as Aristotle’s starkly biological view of the human soul in *De Anima*.” (Lock & Scheper-Hughes, 1996, p. 46). In a western biomedical setting, emphasis is placed on obtaining cure, over and above the emotional dimensions of care, or the “things that are done to make daily life more bearable,” (Mol, 2008, p. 1). As such, actions deemed outside the scope of physiological cure are less valued in professional settings or deferred entirely to family. Yet, both the technical and emotional dimensions of care “may have similar effects on the body” (Mol, 2008, p. 1).

The way health practitioners come to know the body and how particular kinds of knowledge are legitimized as truth is reflective of the nature of the model of reality in operation in a given system of medical knowledge. Following the interpretive understanding of medical knowledges as culturally mediated systems of belief, which – even within the hegemonic system of biomedical knowledge – are enacted differently in specific settings, it is helpful to conceive of medical knowledge as explanatory models of reality (Baer et al., 2003). Social theorists in this area tend to illustrate biomedical knowledge as grounded in a compartmentalizing epistemology, creating dualisms such as between the mind/body and physical/social. For instance, Leon Eisenberg, a social psychiatrist, frames this disjuncture in biomedicine as the distinction between disease, as the object of medical intervention, and illness, as a patient's subjective experience of changes in their state of health (Eisenberg, 1977). Eisenberg has discussed how models of reality are used to determine the appropriate course of medical action. Neglecting the emotional dimensions of care means that the socio-economic factors contributing to illness experiences and the affects of care are superfluous to the task of curing, managing, or preventing the spread of disease. Importantly, once in place, models act to generate their own verification by excluding phenomena outside the frame of reference the user employs. Models are indispensable but hazardous because they can be mistaken for reality itself rather than as but one way of organizing reality.

Thus, models of reality, particularly models of disease, operate as the verification of action by highlighting what kinds of information are determined as useful and how this information is applied toward the task of caring for the ill. When care is reduced to the technical and practical efforts to treat disease, these broader aspects of illness experiences

and the role of care in mitigating the social, psychological, or spiritual dimensions of suffering are neglected. This is reinforced within clinical medicine through “its commitment to a fundamental opposition between spirit and matter, mind and body, and (underlying this) real and unreal” (Scheper-Hughes & Lock, 1987, p. 8). Because the affective ramifications of care are excluded from the reality of disease, they are therefore beyond the realm of biomedical modes of care. This in turn shapes “the economics of health services, the political economy of research, the culture of bureaucracy, and moral worlds of medical schools and clinical institutions [which] have effectively removed caregiving from what matters most in medicine” (Kleinman & van der Geest, 2009, p. 164). The biomedical moral world of care materializes within standard procedures practiced in health care encounters. For instance, emphasis may be placed on the number of clients seen in a day because what is most valued is the number of “services” provided, for example, prescriptions written, medications or immunizations administered, and lab tests ordered.

In *The Birth of the Clinic*, Michel Foucault discusses how the creation of medical knowledge about ephemeral experiences of symptoms rests upon a “reductive discourse” which delineates the human body into a series of functions to be alienated, examined, and removed from social context. The means by which modern biomedicine reconstituted the human body is through the “medical gaze”. This was initiated by advances in visual technology that enabled medical scientists to further explore the interior and microscopic dimensions of the human body (Foucault, 1973). Reflecting on their ethnography of medical students at Harvard University, Byron Good and Mary-Jo DelVecchio Good have also discussed how the medical gaze is conditioned within doctors attending

medical school, through a process of reconstituting conceptualizations of personhood and the body (Good & Good, 1993). Owing to these new conceptualizations, student doctors are taught new meanings and ways of interacting with other bodies, such as through anatomy labs, where students develop new forms of etiquette towards the human body. Good and Good have argued that developing a medical gaze, and thus competence as a physician, requires discounting a patient's psychosocial narratives.

Interestingly, for Good and Good, this compartmentalized, mechanical vision of the body does not impose the substitution of one understanding of the body for another, but rather offers one way of knowing the body, out of multiple possibilities. They discuss that the medical students tended to have an awareness that they were developing a new way of viewing reality which they would consciously apply. Good and Good noted that "cultural work" is required to reconnect on other terms with an individual who has been objectified by the medical gaze (Good & Good, 1993, p. 97). It is through this dynamic that caring comes to take on a contradictory role in biomedical practice. This points to the existence of multiple ontologies which health care providers actively negotiate while responding to the competing pressure of patients, management, time, resources, and their own embodied capabilities and subjective evaluations of a given situation.

Similarly, Lock and Nguyen assert that "biomedical technologies are not autonomous entities, the effects of which are essentially uniform whenever they are put into operation" (Lock & Nguyen, 2010, p. 5). Biomedical knowledge consists of a contradictory combination of formalized and institutionally regulated knowledge acquired through extensive training, combined with a different kind of situational knowledge gained through clinical practice (Taylor, 2003). Local moral worlds of care

are shaped by models of reality that inform how the body and illness are regarded and attended to. However, these models of reality are never operating discretely but comingle between a multiplicity of ontologies of care as doctors, patients, management, and families draw from and evoke these ontologies of care.

The medical gaze and associated models of reality that focus on disease as a technical problem shape the ethics of caregiving by valuing certain aspects over others. Care comes to be framed as a financial transaction that is temporally bounded, with a focus on identifying and treating a pathology which can be identified through biomedical diagnostics. In contrast, a relational view of care recognizes that an act of care continues to influence lives socially and emotionally well beyond the moment of interaction. Reframing “being present” as a means of accomplishing “work” complicates the biomedical objective of identifying and alleviating physiological pathology.

Saasin, a Uchucklesaht community member, reflected on what he felt was a culturally safe approach taken by the director of a local hospital by making an effort to connect with the community.

She has come to functions ... and I have seen her active and it was really uplifting to me to see her there. And to know that she was talking about, willing to know about cleansing, that there can be a place for cleansing to be done. Because we pray and we cleanse and we do those things sometimes once a year, sometimes with just with water and sometimes with smoke. So, it seemed like she was really open to open the doors to say it's acceptable and its good medicine. And I could see, um, *connection*. She has a connection with people, which to me is healing. You know that kind of energy. A doctor can be a doctor, a psychologist can be a psychologist. But some of the training is not to be emotionally attached. But when they are emotionally attached, there is something that they are contributing and they are saying, okay, this person has compassion and has care for me. And it seems *real* (interview, June 13, 2018).

Saasin was inspired by the hospital director's openness towards Indigenous healing practices, yet what really stood out was the opportunity for emotional connection which he describes as required for healing to become "real".

We may turn again to the existence of multiple ontologies of care which are linked with models of reality that inform medical practice. In a biomedical model, a disease is "made real" through the detection of physiological abnormalities using diagnostic technologies, which in turn inform the actions required to provide care. In a relational ontology of care, connection is necessary for care to become real. But what would it mean for care to be real or not? Maori scholar Linda Tuhiwai Smith states that "what makes ideas 'real' is the system of knowledge, the formations of culture, and the relations of power in which these concepts are located" (Smith, 1999, p. 48). Ultimately, it points to what is counted or discounted as pertinent to the goal of alleviating suffering, and the actions taking in addressing this goal, and whether we feel cared for.

By addressing ontologies of care, I am contributing to older conversations about divergent "definitions" of health within an Indigenous worldview. Medical anthropologists have contrasted between a biomedical definition of health as the absence of disease and Indigenous definition that are more holistic, including emotional, spiritual, community, and cultural dimensions of wellbeing (Adelson, 2000; Culhane Speck, 1989; Levesque et al., 2013). While elevating Indigenous definitions of health was a significant contribution, I do not agree that understandings of health are neatly divided between patients and healers. Every health encounter involves a dialogue (which in some cases results in a silencing) of

multiple ontologies of care informed by medical training, workplace norms and pressures, popular explanatory models, family expectations, *hahuupa* (cultural teachings), and previous personal experiences. I also disagree that biomedicine care is inherently antithetical to the emotional and social dimensions of health. Instead, I view the problem of divergent definitions of health not as a clash of incommensurable worldviews, but as a clash of priorities and ethics.

Can Recognition Heal?

The compartmentalizing and objectifying tendencies of the medical gaze are not simply the by-product of a particular model of reality. They are imbricated within power structures and biopolitical governance. Thus, structural racism and settler colonialism as a logic of elimination (Wolfe, 2006) influence the ways in which bodies are objectified and which aspects of care are valued over others. For instance, the devaluation of relational aspects of care as superfluous to the task of curing is linked to the devaluation of Indigenous worldviews. This is strongly apparent through the persistent forms of discrimination faced by NTC nurses. Early on in my field research, I was surprised to hear so many NTC nurses complain that “Island Health [the regional health authority] does not see us as real nurses.” One nurse explained that she thought this was due to “working through another lens, it’s different than what people are used to.” Fay’ama Nuči, a Community Health Nurse in the northern region, explained that there was a perception that “you work for First Nations communities because you couldn’t find a real job” (interview, March 28, 2018). Overall, many nurses described collaboration with other health care providers as paramount to reducing barriers and providing care

continuity. However, discrimination against nurses who work in Indigenous communities has stymied collaboration.

The discrimination against nurses working in Indigenous communities operates in the context of systemic racism against Indigenous patients, which has also contributed to a history of ostracization of Indigenous nurses in medical schools (Meijer Drees, 2013). Thus, there are many interrelated factors contributing to the disregard of Indigenous nursing; a history of settler colonialism which has perpetuated the displacement and assimilation of Indigenous peoples, biopower which perpetuates systemic racism towards Indigenous patients, bureaucratic indifference which, through historical blindness, works to separate the colonial history from how current health inequities manifest, as well as the devaluating of Indigenous knowledge. In this context, recognizing relational care requires shifting values in biomedicine by elevating Indigenous knowledge and approaches to healing.

The contemporary political climate in Canada is (and has been for several decades) defined by the ideology of liberal cultural recognition. Liberal cultural recognition is associated with late capitalism and neoliberal governance, particularly in terms of the relation between state and Indigenous peoples in settler colonial nation states (Povinelli, 2011). In contemporary late liberalism, recognition is the legal framework through which marginalized groups assert their claims to political and cultural self-determination (Coulthard, 2014; Simpson, 2014). Liberal philosophy holds that the granting of state recognition to Indigenous or minority groups is a way through which “diverse states can indeed recognize and accommodate a range of group-specific claims without having to abandon their commitment to a core set of fundamental rights”

(Coulthard, 2014:29). Thus, recognition aims to enable the accommodation of difference by reconciling subaltern claims with the aims of the nation-state⁵². However, it is also the means through which alternative social projects can be accommodated while ultimately incorporated and governed in western democratic states (Povinelli, 2011).

As situated within debates on state recognition of marginalized groups and cultural pluralism in health care, this research is a partial conversation in the broader narrative of late colonial encounters in Canada and how difference is accommodated, contested or otherwise negotiated. As history reveals, how difference has been attended to by the state in the Canadian context has changed over time or unfolded differently in different regions. For instance, Dene political scientist, Glen Coulthard, discusses how Aboriginal policy in Canada has evolved from:

A structure that was once primarily reinforced by policies, techniques, and ideologies explicitly oriented around the genocidal exclusion/assimilation double, to one that is now reproduced through a seemingly more conciliatory set of discourses and institutional practices that emphasize our recognition and accommodation (Coulthard, 2014:6).

Over the past century, interactions between the state and Indigenous peoples have shifted from a policy of overt assimilation to liberal values such as multiculturalism, equality,

⁵² The contemporary framework of recognition operating within liberal settler states is derived from Hegel's *Phenomenology of Spirit* (1807) (Coulthard, 2014; Simpson, 2014). In this theory, Hegel provides the anecdote of the 'master/slave dialectic' in which intersubjective recognition by self-conscious actors represents a universal human need⁵². In Hegel's dialectic, the master remains unrecognized because the slave is not a self-determining agent. As such, the master loses a sense of certainty of himself, and through the master's growing dependency, the slave realizes his own importance. This transforms the relationship into one of balanced mutual recognition, as were the slave to simply replace his master, he would experience the same fate of misrecognition (Coulthard, 2014). Thus, liberal politics of recognition are fundamentally connected to the assumed attainability of mutual recognition.

and sameness under the law (Coulthard, 2014; Vowel, 2016). This shift coincided with the rise of international humanitarianism, Indigenous rights movements, and truth and reconciliation commissions conducted in “post” colonial nation states (Million, 2013). In Canada, this translated into “policies of recognition” (Kelly, 2011).

However, Indigenous scholars have remained critical of the notion that recognition is an appropriate route for attending to ongoing colonial dispossession, and how much this shift in language has actually led to shifts in health status and community control over services (Alfred and Corntassel 2005; Coulthard 2014). They question whether it is possible to forge equitable relationships between the Canadian Government and the Indigenous peoples who have been forcefully incorporated (or displaced) by the settler state. As Coulthard has stated, “where ‘recognition’ is conceived as something that is ultimately ‘granted’ or ‘accorded’ a subaltern group or entity by a dominant group or entity [it] prefigures its failure to significantly modify, let alone transcend, the breadth of power at play in colonial relationships” (Coulthard, 2014:30-31). He questions how mutual recognition can be attained when the terms on which recognition are granted are almost wholly determined by the holders of power.

Indigenous scholars have also argued that the politics of recognition in Canada operate as a form of governmentality which reproduces colonial rule and ensures the production of ‘colonial subjects’ (Alfred & Corntassel, 2005). The politics of recognition do so through “the ability to entice Indigenous peoples to *identify*, either implicitly or explicitly, with the profound *asymmetrical* and *nonreciprocal* forms of recognition either imposed on or granted to them by the settler state” (Coulthard, 2014, p. 25). In light of ongoing dispossession and the non-mutual terms through which recognition is granted,

participation in such processes locks Indigenous communities in an oppositional binary where political actions are directed in compromise or contradiction to the imposition of the settler state, rather than in the best interest of communities (Alfred, 2005b).

Health Transfer Policy

A case example of the politics of recognition in Canada is the Health Transfer Policy (discussed in Chapter 3). Critics of the transfer program have claimed the program is an attempt at cost shifting, wherein “the federal government has actively sought to distance itself from health care service provision by way of transferring responsibility to the provinces and First Nations under the guise of supporting community control and autonomy” (Kelly, 2011, p. 4). Many communities who have undergone health transfer, the NTC included, “complain that the bureaucratic demands are high, that programming is inflexible, and funding too limited” (Kelm, 2004, p. 347). In the case of the Health Transfer Policy, the liberal mandate to “recognize” Indigenous self-determination over health care aligns neatly with neoliberal interests that prioritize devolution of government responsibility to the local level or private sector (Jacklin & Warry, 2004; Million, 2013; Povinelli, 2011)

In his work with the North Shore Tribal Council in Ontario, Wayne Warry outlines the tensions between diverging interests between First Nations communities, what the tribal council advocated for, and what the federal government was prepared to accept in terms of a transfer agreement (Warry, 1998, p. 97). To complicate matters further, because the federal government rejected much of the North Shore Tribal Council’s funding proposals, the tribal council also had to collaborate with provincial programs to acquire additional funding. Similar to the Nuuchahnulth Tribal Council,

funds for the expansion of services available to community members requires competing for funds or contracts made available through the FNHA or regional Health Authority.

Though the Health Transfer Program essentially recognizes Indigenous self-government, it fails to uphold Indigenous sovereignty. The health transfer process has been criticized as working to reduce federal spending on First Nations health by putting more onus on communities to apply for health funding (Warry, 1998). Indeed, transfer agreements actually limit funding, “by way of a non-enrichment clause, to health care delivery costs at the time of transfer” (Kelly, 2011, p. 3). In such a climate, ongoing evaluation and the ability to demonstrate efficiency is key to securing external or renewed funding for services. Thus, tribal councils and Indigenous organizations are caught between accountability to the communities they represent, and the terms of transfer agreements which are largely defined by the federal government.

Additionally, the scope of health funding transferred to Indigenous governments is limited to interpretations from the Indian Act (1867), defined to prevent infectious disease, rather than addressing demonstrated causes of health disparity (Jacklin & Warry, 2004). Overwhelmingly, assessments of the Health Transfer Policy have revealed that community control is actually curtailed because the locus of control over funding and the renewal process remains with the federal government (Jacklin & Warry, 2004; Peters & Self, 2005). In other words, “the Transfer Policy proposes that a larger share of the “responsibility” now allocated to the federal government be shouldered by First Nations without a larger share of the power” (Culhane Speck, 1989, p. 221).

Those employed at the NTC are constantly reminded of this imbalance, as they work to meet regular reporting requirements and demonstrate the efficacy of the

organization, even when this contradicts the needs expressed by community leadership. A stark example of this can be seen in the 2019 disbandment of an Indigenous organization on the west coast that had undergone a health transfer decades prior. The organization was subjected to auditing and it was determined by the First Nations Health Authority that they were “too generous” with their travel expenses (field notes, July 11, 2019). NTC nurses explained that this unauthorized expense was for medically necessary travel for patients, but that the expense lay outside of the prescribed funding streams. Speaking with a group of NTC nurses in one of the offices, λusmit offered a similar example in the Nuu-chah-nulth communities:

So, the 80-year-old man living over there [points out the window to the Tseshah reserve] can’t get support to travel to the hospital in town, or for his doctor’s appointment that is a 20-minute drive away. So again, it’s that something is being promised to the community and then taken away (field notes, July 11, 2019).

This comment emphasizes how tenuous federally assigned “self-determination” over health care is. At the NTC, these pressures are shouldered by the nurses who are accountable to the community members they care for, even though the gaps in services are the result of restrictive transfer agreements.

Another example illustrates this point, when a community member had recently returned home after surgery and required wound care. NTC nurses have been unable to provide wound care because it is outside their scope of practice as defined by the transfer agreement. Yet nurses from other jurisdictions, such as the regional health authority, will not travel on reserve because individuals living on reserve are not part of their client load. Tribal councils must ensure they continuously deliver the same standard and availability of care (above and beyond structural pressures such as challenges recruiting and retaining

staff) and must follow mandated rules exactly, even if they exacerbate health inequities, otherwise the funding can be pulled.

As the case of the Health Transfer Policy clearly demonstrates, “by allowing Indigenous peoples a small measure of self-administration, and by foregoing a small portion of the moneys derived from the exploitation of indigenous nations’ lands, the state has created an incentive for integration into its own sovereignty framework” (Alfred, 2005a, p. 44). Indigenous organizations are integrated into a biopolitics founded on health inequity. Health services are limited to static, underfunded, and under resourced agreements which perpetuate limited access to health services. Indeed, studies have shown that funding per capita is significantly lower in comparison to spending on provincial health services (Czyzewski, 2011). The difference is that responsibility and accountability have been shifted from the federal government to Indigenous organizations and tribal councils. While this can certainly be attributed to divergent definitions of what constitutes health, it also produces contradictory ethical obligations to clients and to the sustainability of self-governance of health services. Furthermore, efficacy measured in terms of the completion of “tasks” in a model of reality that frames care as the alleviation of disease (at the expense of other aspects of illness experiences) places the relationships and promises made between leadership, communities, nurses, and clients at stake. Liberal recognition of Indigenous self-government works to perpetuate an exclusionary biopolitics, ultimately rooted in settler colonialism. By “granting” self-government of health, the federal government absolves itself of the responsibility of administering subpar health services. Instead, the burden is shifted to Indigenous nurses and community health leaders to meet the needs, wishes, and values of care held within Nuuchahnulth

communities, as an alternative to what liberal recognition framed within a colonial biopolitics is willing to offer.

Cultural Safety Policy

Cultural safety and its manifestations in health policy present another site of contradiction between liberal recognition and the modes of care and local moral worlds that exceed the parameters of biopower. The concept of cultural safety can be framed as a response to the politics of cultural recognition, and the failure to advance material rather than merely symbolic shifts in power. However, at the same time, as cultural safety gains traction in Canadian health policy, it is integrated into pre-existing paradigms including liberal recognition and biomedical models of reality. As such, what happens when conventional guidelines-based care practices attempt to attend to the highly personalized dimensions of care such as cultural safety? Initially developed within nursing theory, the concept of cultural safety has come to take on various interpretations as health policy organizations attempt to translate it within their mandate.

Throughout the interviews with NTC nurses, the concept was eloquently described as necessary to provide care to clients, otherwise their services would be refused. The nurses described cultural safety as a relational approach that required engaging with clients in their role as a nurse but setting aside any agenda, expectations, or time limits. Other key ways in which this approach was defined included a client-led approach and acting as an advocate. Indeed, key themes that arose in community interviews centered around the importance of clients maintaining autonomy over their treatment and being “taken seriously”, the issue of fairness (including receiving access to and quality of health services comparable to that of the general population), and fostering

understanding (of clients' illness experience and the social, economic, emotional and other determinants of health impacting their ability to seek and/or follow up on treatments).

While cultural safety is described as complementary to Indigenous worldviews, it is important to consider how an imported concept can be implemented in ways that empower local beliefs and expectations for care rather than displacing them with a more generalized assertion of pan-Indigenous wellness⁵³. This is because culturally safe care has yet to be fully realized in health care delivery. First, there is a disjuncture between the ideal of cultural safety as it is defined in health policy commitments and the voices of those I spoke with, who emphasized dehumanizing and dismissive health care experiences. Second, there remains a generalizing and top-down nature in health policy discourse. The standardization of cultural safety, as it is incorporated into policy frameworks, runs the risk of closing off the potentialities enabled through affording space for multiple ontologies of care, while at the same time the ethics of care are expanded by the introduction of cultural safety.

The “facticity” (Haraway 1993) of biomedicine paired with guidelines-based care (Sobo, 2009) sets biomedical discourse, interventions, and organizational structures on a course towards asserting increasing homogeneity and standardization. In practice, the

⁵³ In some ways, this concern has been addressed by the FNHA through a commitment to “an understanding of what health and wellness means to First Nation individuals with recognition of the diversity of these understandings” (First Nations Health Authority, 2015, p. 10), as well as the emphasis on *cultural humility* as a commitment on par with, and an enabler of, cultural safety. According to the FNHA, cultural humility depends on self-reflection on the part of health care providers and a commitment to listening to patients and learning about their backgrounds without imposing one’s own values. Such self-reflection can reveal “personal and systemic conditioned biases, and to develop and maintain respectful processes and relationships based on mutual trust” (First Nations Health Authority, 2015, p. 11). It also implies a humble acknowledgement that understanding the culture of others is a life-long process.

ideal of standardization is never realized, yet it remains the status to be achieved. By homogeneity in medical discourse, I am referring to assumptions and professional standards around what care should look like, what all patients are like, what patients really need when they are presenting in a particular manner, what is or is not ‘professional’ nursing, or how culture can or should be incorporated into clinical practice. This striving for standardization ultimately leads to the closing off of cultural safety as a concept. When clinical practice is written into a set of procedures, the possibilities and potentialities associated with initially subversive concepts such as cultural safety are contained and bounded within a set of guidelines. Very often, the enactment of these homogenizing discourses around what care looks like, how patients should present, and how they are attended to manifests as discrimination. These homogenizing discourses are experienced by patients as not being listened to, being stereotyped, or dismissed. Therefore, the work of anti-discrimination within the health system relies on carving out spaces for multiplicity, or to make explicit the multiplicity of care ontologies within biomedicine, which have always been there.

Conclusion: “NTC Nurses are the Beginning of Something Good”

In Port Alberni on a summer day, I enjoyed a cup of tea in the kitchen of Našuk, an Elder from Uchucklesaht First Nation who is also a professional artist and a residential school survivor. While talking about the NTC Nursing Services, she explained that the “NTC nurses are the beginning of something good. They are totally different from how things were done in the past” (June 21, 2018). Našuk compared NTC nurses with the forced x-ray examinations for tuberculosis conducted in her community, which could sometimes

lead to community members being sent away to the Nanaimo Indian Hospital. While Indian hospitals are no longer in operation, this comparison does attest to the kinds of trauma associated with the health care system many Nuu-chah-nulth-aht have experienced, and which NTC nurses strive to reconcile alongside clients. This requires both working through while also working differently from biomedical standards.

At the same time that relational care is circumscribed, these modes of care also work to break down the structural exclusion described in Chapters 4 and 5 as a condition of biopower. This occurs by making care more accessible and deconstructing pervasive stereotypes by affording patients to be seen as individuals with hopes, values, and lived realities that influence the ways in which they access and experience health care. By having an in depth understanding of clients' lived experiences as well as their hopes and beliefs, NTC nurses are well-positioned to support clients through challenging or traumatic events or healthcare experiences.

Indeed, many of the NTC nurses reflected that their position enabled them to “be a part of the success stories”. A NTC Home Care Nurse explained that:

To see those success stories, for me, is just the most rewarding thing. And it doesn't have to be changing the whole community. It's just if you've touched one person, because of the way that they live, that one person is affecting the family which is affecting the community. So, it has that ripple effect (NTC Home Care, December 7, 2017).

In this sense, culturally safe and relational nursing care work as a catalyst for community healing. The connections between individuals, families, and communities as an extension of the “self” work to circulate and expand the affects of hope and recovery through the effectuation of *caqaalth* (persisting feeling of connection and support). In many ways, this “ripple effect” also produces reverberations in health care more broadly.

As an NTC nurse with experience working in harm reduction explained:

There's lots of aha moments. Where you're working with someone, where they are struggling inside, sometimes their demons inside or whatever. And all of a sudden it clicks. Right? They are able to go to a treatment centre. And they come back and get custody of their kids. You know, you know the struggle they've been through. And you see them later and they are doing amazing (interview, December 14, 2017).

In her work, she found that her clients confront numerous barriers to addressing their health concerns, including poverty, homelessness, substance use, stigma, and racial discrimination. A relational nursing approach allowed her to break down some of the barriers associated with stigma and discrimination by being a persistent and trustworthy advocate.

Elevating Indigenous approaches to healing, specifically relational modes of care, requires redefining “productive time” by valuing client visits equally with accomplishing “tasks.” Y'am'a, an experienced NTC Home Care Nurse, gave a moving account of how she registers “success” in her nursing practice:

Because of the kind of nursing we do, to me every encounter is a success, one of those positive experiences. I don't think we as nurses, as Nuu-chah-nulth nurses, realize the impact we do have on the care we provide for our clients. I mean one of the, recently, we had a death in Tseshah. And this client literally would connect with me every day that I worked. Whether it was a text, a phone call, two calls, a home visit. It doesn't matter how the connection happened. [Another NTC nurse] and I were such an integral part of her health journey. And we didn't necessarily do anything medical. I mean there was times we ... there were things we did nursing-wise to help her. But I would say three quarters of what we did for her was emotional support, mental support. And she ended up passing away, she was very young. She passed away in June. And her family, her daughter, and her husband, reached out to us. And basically, told us, what they had found, things that she had written about us in her journal. To the point that we were asked to be honorary pallbearers at her funeral. So that's usually reserved for very close family members, people that have been part of their lives all their life. Those positions are not taken lightly, that's one of the highest respectful things you can do. And [another NTC nurse] and I we're both given that. So, it just, to me showed that how, even though we have a five-minute conversation, we don't feel like we are doing anything

nursing. But the impact that we are having is huge (NTC Home Care Nurse, December 7, 2017).

By being asked to be a pall bearer, the young woman's family acknowledged the significant impact the NTC nurses had in her life and towards her wellbeing. No cure was available for this young woman, yet we can extrapolate from this story that the NTC nurses' efforts to care—both practically and emotionally—for this client greatly impacted her quality of life.

Y'am'a told this story when I had asked if she had positive experiences treating patients that she could share. Afterwards, she paused, wondering if she had properly answered my question because she hadn't talked specifically about "treatments," or even the specific ailments the client had faced. I encouraged Y'am'a that I thought she was touching on something important, perhaps the different ways we might think about taking care of one's health. She responded:

Because what is health? Really what is health? Is it taking care of an open cut, is that health? What is our purpose? That's a part of the Aboriginal wellness wheel, right? It's physical, mental, spiritual, emotional. You know that balance of finding that in that wellness wheel. And so, as nurses, that is what we have to look at, and be concerned with. That we are not just there for the physical health. There is the mental, there is spiritual, there is emotional. I mean it is the whole thing right. And part of understanding that is looking within ourselves and seen where am I in my wellness wheel? So, I think for us to really be able this kind of work as best we can, is that we really need to be balanced, ourselves (NTC Home Care Nurse, December 7, 2017).

By posing the question, "what is health?" Y'am'a brings attention to the tension between advocating for Indigenous approaches to healing, and actually bringing it into practice through an attentiveness to the emotional, spiritual and relational aspects of wellbeing. In a relational model, even the care provider's state of health (holistically understood) contributes to whether an increase in health or quality of life is achieved through the act

of providing care. As implicated participants rather than discrete autonomous individuals, patients, healers, and the social networks they are embedded in are accountable to the affects and outcomes relating to a health care encounter.

In this sense, I find Stevenson's formulation of care as the intentions and actions that suspend between social and bureaucratic relations particularly illuminating (Stevenson, 2014). For Stevenson, understanding care, and the impacts of practices of care, relies on situating it within social relations, as "acknowledging the way our lives are not our own, the way we are called and call others, opens the space for the ethics of care" (Stevenson, 2014, p. 17). This "ethics of care" requires us to "listen differently to the lives and imaginations of the people who matter to us" (Stevenson, 2014, p. 174) and thereby open ourselves to an understanding of how some modes of care can have detrimental effects, while other forms of care may emerge in unanticipated yet healing ways. Stevenson is suggesting that the route to establishing ethical forms of care for Indigenous communities requires being attentive to how moral obligations are constituted differently through the process of care in different social contexts.

A health leader at the NTC once described to me the work of the nursing services as "renovating one room in the house at a time". I was told by NTC management that the health transfer is a "live practice" that must constantly be nurtured. Working to promote health in the context of health inequity, the efforts of nurses and community leaders contribute to an unfinished, imperfect social project. While they may make strides in some areas such as initiating a mobile diabetes clinic, the accomplishments of the NTC are always bounded by the systemic devaluation of Indigenous knowledges, the normalized racism community members are subject to in hospitals and clinics, and self-

governance frameworks that circumscribe at the same time as they grant community control over health services. Looking at the intersections between NTC nursing, the broader health system and health policy provides an opportunity to unravel these complexities to make visible these efforts and to identify opportunities for change.

The politics of recognition and discourse around self-determination provide the social and political context through which contemporary Aboriginal health policy is being developed in Canada. Considering this tendency of the politics of recognition to be granted on non-mutual and conditional terms, to reproduce colonial subjectivities, and to mask the ongoing material implications of dispossession and marginalization, it remains questionable as to whether recent changes in policy truly address inequity in access to health care and enable the provision of culturally safe services. Yet it has always been the advocacy of Indigenous families and community leaders that have driven these changes. These sites of care continue to be the locus of transformation in Canadian health care.

This is perhaps best explained with a story. In a Northern Nuu-chah-nulth community, there is a non-Indigenous family who have been working as nurses in the community for multiple generations. They have a family story that goes as follows: women from the community would call the outpost nurse complaining of various symptoms. However, when the nurse arrived, she would find her patient in active labour. The women from the community had lied so that they wouldn't have to evacuate from the community for childbirth. As this became a pattern, the nurse would always go along with the calls but had learned to pack supplies for childbirth. Eventually, the nurse was ceremonially adopted into the community for her role in delivering the children of the community. The same family of women have been tending to the health of the

community for generations, and the trend continues. This collaboration between community and nurses offers a powerful example of self-determination that operates outside of policy frameworks or liberal recognition. Indeed, subversion of standard procedure was required on the part of the nurses in order to promote the health of the community on their own terms, i.e., staying in community for childbirth. It is this combination of working alongside and subverting, sometimes even simultaneously, that makes it so difficult to assess recent developments in Aboriginal health policy in western Canada.

In this respect, I find Diane Million's two definitions of self-determination particularly illuminating. Drawing from the work of Maaka and Fleras (2008), she explains that:

One [definition] is an inherent Indigenous autonomy that honors "distinctive ways of looking at the world," that makes these distinctions part of the partnership and critically recognizes that "Indigenous peoples alone possess the right to decide ... what is best". The other is a state-determined devolution of its own forms to allow for a neoliberal self-management and self-sufficiency (Maaka and Fleras, 2008, cited in Million 2013, 4).

Based on these two contradictory and coeval definitions, Million questions "on what terms is 'self-determination' offered in this political moment?" For instance, does cultural safety and the health transfer policy in their current form support self-determination, nation-rebuilding, and community-led healing? Perhaps we should also consider these policy frameworks as renovating one room at a time as well. Importantly, is it possible to advocate for, implement, and become subject to these policies while also maintaining attention on persisting structural racism and settler colonial logics that inform Canadian biopolitics?

When theorizing biopower, I am cognizant of the limitations of a poststructuralist theorization of biomedicine. Medicine is very much about power, but it is also more than techniques of governance. For instance, Donna Haraway has identified that “scientific discourses are ‘lumpy’; they contain and enact condensed contestations for meanings and practices” (Haraway, 1993, p. 365). Biomedicine is not deterministic, uniform or non-malleable: biomedical knowledge and techniques can and do shift under countervailing pressures. For instance, Good and Good have demonstrated that the biomedical gaze is only one particular way of coming to know the body, one that is consciously cultivated and applied by doctors as they learn the ‘art’ of medicine (Good & Good, 1993). It is through inconsistencies such as these that biomedical practice is revealed as something that – while operating on institutionally structured sets of knowledge – can be enacted differently in different contexts, by different physicians and towards different patients. It is in this space of indeterminacy or creative interpretation that alterity coexists alongside techniques of governance.

Veena Das and Deborah Poole have addressed the coexistence of “the margins,” or marginalized populations, alongside dominant political and regulatory processes. They suggest that “the indeterminacy of the margins not only allows forms of resistance but more importantly enables strategies of engaging the state as some kind of margin to the body of citizens” (Das & Poole, 2004, p. 30). This sentiment reflects the dichotomy presented by the NTC nurses between relational and mainstream nursing, where mainstream nursing presents a site of oppression (through paternalistic relationships with clients) and exclusion (through discrimination), which clients rightfully resist or advocate against.

I have mentioned that the modes of care I have illustrated as operating within Nuu-chah-nulth communities have persisted both before, alongside, and in response to colonial pressures. It is through the persistence of *hahuupa* (cultural teachings) and *ha'wiih* (hereditary chiefs), that the “strong and persistent social structure, medicine, as a colonial tool for culture change, can be contained and redirected towards decolonization” (Kelm, 2004, p. 336). In her analysis of cultural recognition in the context of late liberalism and alternative social projects within this context, Povinelli demonstrates that:

although it can police the potential eruptions of political events, the politics of cultural recognition in late liberalism cannot saturate social worlds in such a way that no potentiality remains within the actual world. This is in part because, in relation to social projects and worlds, recognition only faces one aspect, or plane, of these projects and worlds, and because trying to manage this plane creates new potential for these projects and worlds (Povinelli, 2011, p. 72).

In the process of “bracketing off” social worlds to deliberate on how they should be governed, particular events or actions of concern are divorced from the social worlds they refer to. For instance, relational nursing may be governed through the need to achieve imposed parameters such as immunization rates, or funding may be allocated only for specific actions (travel expenses for nurses conducting immunizations) but not others (travel costs for patients requiring specialized medical attention). Meanwhile, the ontologies and social worlds which relational care speaks to persist. They live on alongside with, in contest to, or camouflaged from imposed parameters and techniques of governance.

Povinelli draws on Deleuze to explain how “the perpetual variation between *vis existendi* and *potentia agendi* – between striving to preserve and any actual idea or action that emerges from this striving – provides a space of potentiality where new forms of life

can emerge” (Povinelli, 2011, p. 9). I understand this as the space between affects and outcomes; between enduring what is on hand and actively responding to it. This is where new worlds of social possibility emerge. This is the transformative potential inherent to care. It is in this way that the indeterminacy of the margins and the interaction between power and forms of resistance produce incremental changes within the moral worlds of biomedical care. In this way, no single set of policies – or demonstration against existing policy – can be isolated as the source of social change. Rather, social change can be conceived of as the complex interactions between networks of care including the daily efforts of NTC nurses, community gatherings, calling someone with one’s mind, or hospital directors who make an effort to connect with Indigenous communities.

The indeterminacy of biomedicine and recognition enables the persistence of alternative social projects, not only to persist but to assert influence by shaping conversations on the ethics of care. It is not just that these alternative social worlds persist in “the brackets of recognition” but that they are active, creative, socially productive sites of survivance. The reproduction and enactment of a relational ontology of care and the ethics of implicatedness, of *hishook-ish tsa’walk* (we are all one), work to shape the ethics of care broadly. It is a multidirectional assertion of influence, which doesn’t have to occur through large scale demonstrations, but occurs every day when an NTC nurse knocks on the door of a community member, when a young person sits with an Elder, in *oosumich* (spiritual cleansing), and in communities coming together in celebration. These various acts of care provide the “seeds of resurgence” of Indigenous healing (Simpson, 2011). These modes of care are brought into the light of recognition through interactions between Indigenous leaders and health care professionals and health policy, such as when

NTC management advocates for better access to health services, when new agreements are drawn, or when health governing bodies such as the FNHA conduct community outreach. Through these interactions, Indigenous approaches to healing open up conversations on the ethics of care; how to preserve the dignity of patients (and why this is necessary) and taking accountability for ongoing harms. This process unfolds as an imperfect, uneven, but open-ended dialogue.

Chapter 8: Nation Rebuilding

In this dissertation, I have investigated the various definitions and manifestations of cultural safety in nursing practice and health care experiences, in health policy, and Nuu-chah-nulth communities. The concept of culturally safe care, especially as it has been mobilized by NTC nurses, operates in the boundary between Indigenous healing and biomedicine, between policy and practice, and between individual health care experiences and systemic racism and health inequity. The NTC relational and culturally safe nursing framework draws on both dominant nursing theory and Nuu-chah-nulth values at the same time as it operates as a response to the health inequities faced by Indigenous communities. The NTC Nursing Services actively translate a mandate for cultural safety into practice by practicing reflexivity, collaborating with clients and community, incorporating Nuu-chah-nulth culture in accordance with each client's wishes, taking time, fostering trust, and through advocating on behalf of patients. The NTC relational and culturally safe nursing framework has increased access to care and improved health care experiences by addressing existing trauma associated with health care, supporting clients to overcome personal challenges, providing "deep care" through meaningful and accountable relationships with clients, and challenging structural exclusion by fostering understanding of their lived experiences.

Such efforts are necessary to address the lingering affects which circulate in response to racially discriminatory attitudes and practices in health care which coalesce with the historical trauma associated with the experiences of patients who attended

residential school and Indian hospitals. The political economy of health care delivery in Nuu-chah-nulth communities operates as an exclusionary mode of care and works to fracture relational care networks. Relational care is circumscribed by current health policy through the glaring lack of access to health services in remote Indigenous communities. In these cases, colonial ideologies about centre and periphery delineate what health services and resources are materially available. In western Canada, exclusion continues to operate as a normative mode of care, especially through the implicit bias and stereotypes that demean Indigenous peoples. Implicit bias is reproduced through clinical practices such as failing to plan for post hospital discharge care needs, or through the restrictive appointment policies faced by out-of-town patients. Furthermore, when instances of racist attitudes and behaviors are brought forward, focus remains on the interpersonal dimensions of the claim, rather than the systemic nature of racism in health care. Related to anti-Indigenous discrimination, is a failure to accommodate collective ontologies of care in health services. For instance, the importance of families being together for ill loved ones is undermined by the lack of health services in remote communities, limited medical travel support, and hospital policies.

However, by exploring the sites where self-determination of health services has shown the possibility for more pluralistic and relational modes of care, my objective has been to bring into question the assumption that biomedicine is incapable of relational or, more broadly, Indigenous approaches to care. I would assert that diverse modes of care are not inherently contradictory, but rather are made so as they become subject to Eurocentric cognitive frameworks and reductive guidelines-based health policies. In the interactions between ontologies of care such as in the clinic, emphasis on how they differ

is an inherently political act. For one, claims of incommensurability are often justification for domination (Eckert, 2016). For another, medical anthropologists have long emphasized the difference between western biomedicine and ethnomedical traditions to reveal the shortcomings of biomedical approaches. Constructing incommensurability between ontologies of care can work to both justify and counter oppression. However, my approach has been to apply a relational anthropology to examining the intersections and contestations between ontologies of care. Eckert has described a relational anthropology as a movement “from difference to inequality: only when we consider ourselves comparable, and thus equal to others, can differences be termed inequalities, and only if there is commensurability can such inequalities be unjust” (Eckert, 2016, p. 243). Through this approach, I have demonstrated that anti-Indigenous discrimination is not a matter of differing care expectations nor perspectives, but rather colonial discourses that normalize exclusionary care.

Recommendations for Realizing Health Equity

As a result of this ethnographic research and the collaborative methodology, practical recommendations have been identified both by project contributors and as suggested by research findings. These recommendations highlight tangible changes to current health policy which could mitigate the issues faced by Nuuchahnulth communities in terms of access to health services and the quality of care they receive. These include increasing access to primary care, providing Elder care in-community, providing away-from-home culturally safe health services, expanding and streamlining medical travel aid, eradicating anti-Indigenous discrimination, increasing collaboration across health systems, mentoring nursing teams, and recognizing Indigenous self-determination.

Increasing Access to Primary Care

Culturally safe and relational health care delivery is contingent on ensuring adequate and reliable access to primary care. Increasing access to primary care would ensure individuals would have reliable access to a health care provider who could serve as first contact and site of continuing care. Primary care involves diagnosis and prescription of medications, referrals, and basic testing. Increasing access to primary care in Nuuchahnulth communities requires strong collaboration between the NTC and regional health authority. Actions to increase access to primary care include staff retention, increasing access to family physicians, 24-hour primary care centres in remote regions, and expanding the NTC Nursing scope of practice. Increasing staff retention should apply to physicians, NTC nursing staff, and care aides working within communities. Staff retention could be improved by revisiting pay models, scheduling, and incentives for rural and remote positions to promote long-term staffing and increased time spent in remote communities. Increasing access to family physicians is key to fostering cultural safety by creating opportunities for individuals to build rapport with their family doctor and confidence that a patient's medical history and personal circumstances are known and brought into consideration in treatment plans. Lastly, expanding the scope of practice of NTC nursing could increase access to primary care by developing and expanding remote nursing programs and creating positions for Nurse Practitioners to provide care to remote communities.

Elder Care in-Community

Improving care for Elders in remote communities involves building on the NTC home care program to provide infrastructure and services for Elders to continue to live

comfortably at home. The care aide program can be enhanced through revisiting hiring regulations and incentives, as well as building on existing training opportunities provided through the NTC. Research participants suggested utilizing existing community buildings and resources to create care homes for Elders in community. Another suggestion was to create an employment position for an “Elder’s advocate” who can ensure the needs of Elders in the community are met, including small home improvements, delivering supplies, check-ins, or coordinating with care aides and nurses.

Away-From Home Culturally Safe Health Care

Participants expressed a strong wish for Indigenous-wellness focused care to be made accessible to Nuuchahnulth community members and Indigenous peoples living in urban areas. Suggestions voiced by project contributors included expanding the services provided by NTC to away-from home members and opening a health centre at the Port Alberni Friendship Centre which could offer urgent and primary care, with an emphasis on culturally safe and respectful practice.

Expanding and Streamlining Medical Travel Aid

Recommendations include revisiting medical travel support policies in accordance to actual cost of travel from remote communities, streamlining access to funds, and providing 24-hour telephone service for assisting families with medical travel during emergencies.

Eradicating Discrimination in Health Care

Recommendations for ending discrimination in health care include addressing workplace cultures, enhancing the patient complaint process, centering the expertise of NTC nurses, and expanding cultural safety training. Clinical workplace cultures should be addressed

through mentorship, change management, and zero tolerance approaches for discriminatory behaviors from health care providers. Enhancing the patient complaint process would afford greater anonymity and protection for complainants, as well as responsive follow-up regarding actions made to remedy complaints. Additionally, complainants should be centered as the expert and the dignity of the complainants should be a key priority in any investigation processes.

Centering the expertise of NTC nursing in primary care teams would bring insight into applying a relational and culturally safe approach, as well as a deep understanding of clients' wishes, cultural values, family and medical history, present health needs and lived circumstances, and previous traumatic experiences with health care. Centering clients and their preferred health care provider as experts in health care teams would expand the impact of the NTC relational care approach in increasing access to health care and empowering families on their health journey. Regular opportunities should be made for health care providers working across the continuum of care to meet with NTC nursing teams or to be educated about the NTC Nursing Services and approach, to increase understanding and collaboration across health systems.

Expanding cultural safety training would address the health care providers' lack of knowledge about the history of the residential schools and colonialism in Canada—a point which was highlighted by project contributors. Health policies addressing anti-Indigenous discrimination should emphasize the systemic nature of racism along with the interpersonal manifestations of racism. Strategic plans should identify and address care practices that further marginalize patients (such as hospital discharge planning, as identified in Chapter 5).

Increasing Collaboration Between Health Systems

Increasing collaboration between the NTC Nursing Services, Island Health, and the Divisions of Family practice is necessary for increasing access to primary care for Nuuchah-nulth-aht, as well as enhancing cultural safety across health systems. Collaboration could be supported by exploring information sharing across health care providers, such as hospitalizations, referrals, and changes to health status. Scheduling of locum doctors and other health care providers travel to remote communities should be consistent and transparently made available to NTC nursing staff. Existing joint contracts shared between NTC and Island Health were identified by nurses as important sites of collaboration.

Mentoring Nursing Teams

Several NTC Nursing participants identified that strong mentorship was necessary to supporting nurses in their role as advocates. Facing systemic barriers to culturally safe care alongside clients, as well as supporting clients through crisis and personal loss takes an incredible toll on front-line staff. NTC nurses indicated that this stress could lead to staff turnover. Furthermore, as nurses emphasized, “for us to really be able [to do] this kind of work as best we can, ... we really need to be balanced, ourselves” (NTC Home Care Nurse, personal communication, December 7, 2017). Importantly, nurses wish to expand on existing mentorship provided by Indigenous nurses, Elders, and knowledgeable community members to inform and create opportunities to reflect on their nursing practice. Expanding regular and ongoing opportunities for group reflection and having supportive and receptive leadership were identified as key strategies to providing

mentorship for NTC nurses. The role of Indigenous mentorship in guiding nurses through culturally safe practice could also translate to other areas of the health care system.

Further research is required to determine the feasibility of these interventions and to evaluate the quality effectiveness of care once implemented. Many of the issues and experiences identified throughout this dissertation are shared among Indigenous communities across Canada. Thus, these recommendations provide a starting point to address health equity for Indigenous communities broadly. These recommendations were developed through conversation with Nuuchahnulth community members and health leaders, as well as NTC nurses. Grounding any changes to existing health policy in Indigenous perspectives is fundamental to contending with the relationship between Indigenous peoples and health care systems that have divided families, failed to provide consent to patients, and excluded and marginalized Indigenous peoples. Thus, fostering health equity is intrinsically linked to recognizing Indigenous self-determination.

Recognizing Indigenous Self-Determination in Health Services

The necessity of Indigenous control over health services in the Nuuchahnulth context is evidenced through the development of a unique nursing approach grounded in Nuuchahnulth values and teachings of, as well as the significant impact of the NTC Nursing Framework in increasing access to care and empowering families on their health journeys. The impacts of the NTC nursing services (outlined in Chapters 3 and 7) demonstrate the effectiveness of health services that are in alignment with the wishes and values held within the communities served. A pressing need is to identify opportunities for the regional health system to interface with Nuuchahnulth models of self-determination and governance structures in ways that flows from and further enables the

self-determination of health services from within Nuu-chah-nulth communities. This will be a crucial first step to addressing the unmet health needs and learning from the successes of the NTC Nursing Framework to provide effective and respectful culturally safe health care.

“Nation rebuilding” is a phrase used by NTC leadership to describe a process of regaining healthy communities and strong political influence. By asserting “nation rebuilding”, discussions on Indigenous health are reframed away from a deficit point of view to the re-education of the settler population about Nuu-chah-nulth governance, worldviews, and modes of healing. A former NTC president once explained to me that “the [Canadian] government doesn’t even understand what we need because we have always only been the ‘Indian problem’ to them.” Instead, he argued that the Canadian government should learn how to “plug into” existing Nuu-chah-nulth structures of governance and community organization. On Nuu-chah-nulth *ha’hoolthi*, the *ha’wiith* governance structure permeates daily life. It is the broader recognition of this that is lacking in relations between Nuu-chah-nulth nations and the Canadian state.

Many scholars working in Indigenous health have asserted that healthy communities are necessary to self-determination and vice versa (Adelson, 2000; Culhane Speck, 1989; Czyzewski, 2011; Kelm, 2004). Care, as the individual practices that constitute healthy communities, is vital to processes of nation rebuilding and political change. According to Rabinow and Rose, “medicine is perhaps the oldest site where one can observe the play of truth, power and ethics in relation to the subject, and to the possibilities of a good, or as the Greeks would have it, a flourishing, life” (Rabinow and Rose, 2006, p. 200). In other words, medicine, processes of healing, and health care

encounters, encapsulate a space of social drama where the hope for a better tomorrow (one without suffering) is asserted and either acted upon or dismissed. In this way, “suffering becomes a process of social mediation *and* transformation. It is experienced within nested contexts of embodiment: collective, intersubjective, individual. It absorbs into the body-self the moral world’s contradictory obligations/rights and the norms/contestations of the body politic” (Kleinman et al., 1997). The mediation associated with health care encounters occurs across the construction of racialized otherness, diverging worldviews, and the uneven distribution of socio-economic power. At the same time, the potential for transformation lies within the interdeterminacy of these mediations and the way an individual’s suffering interconnects with historical trauma and lingering affects, or the mobilization of Indigenous governance for better health services. The circulation of affects as an outcome also implicates the potential for transformation. This can be poignantly seen where racial discrimination and implicit bias on the part of health care providers constitute traumatic health care experiences. However, it can also be seen in the potential for relational care to produce *caqaalth* (persisting social connection and support), which, through a “ripple effect” reverberates throughout a community.

Hishook-ish tsa’walk as an Indigenous ontology recognizes spirituality, intuition, and emotion as sources of knowledge and includes unseen spiritual elements as part of an interconnected reality (Atleo, 2004). Rather than viewing reality as a series of cause-effect relationships, reality is constituted through networks of relationships. Such a perspective radically shifts what we may believe care to consist of. It brings attention to the ways we are embedded ethically and morally. In this light, care as a financial

transaction (in the fee for service model applied in BC health care) is woefully inadequate.

Ontologies of care are interesting in terms of what they accomplish as a theory of reality; they are more than simple truth claims. Keane states that “ontologies, as something people might be able to talk about, are a response to the ethical demands of social life (which may include relations with animals and other entities)” (Keane, 2013, p. 188). In other words, all ontologies delineate how we relate to other beings – and whether those relationships remain in focus. A relational ontology “instantiates an ethical imperative to acknowledge and honour the significance of the relationships we have with others, how our histories and experiences position us in relation to each other and how our futures as people in the world are tied together” (Donald, 2012, p. 536). In this sense, care is integral to nation rebuilding, not only by producing healthy communities, but as an opportunity to assert Nuu-chah-nulth ways of being in the world and the ethical entanglements they implicate.

Relational care provides an avenue for healing historical trauma and reshaping biomedical health services. In extension, Indigenous self-determination facilitates transformative health care experiences by re-establishing relational care networks. This configuration of self-determination, or nation rebuilding, is contingent on

a rejection of the models of government rooted in European cultural values. It is an uneven process of reinstituting systems that promote the goals and reinforce the values of Indigenous cultures, against the constant efforts of the Canadian and United States governments to maintain the system of dominance imposed on Indigenous communities during the last century (Alfred, 2005a, p. 40).

In “reinstituting the values” of the Nuu-chah-nulth people, NTC nurses are uniquely positioned to assert the importance of Indigenous relational modes of care, as

they work within the “intersection of public policy and personal lives” (Woods, 2012, p. 61). Indeed, the enactment of Nuuchahnulth relational modes of care is influencing standards in biomedicine by bringing to the fore conversations about the ethics of care. For instance, I was aware of growing momentum of a discourse among hospital staff that a relational care approach, such as practiced by NTC nurses, could mitigate the pervasive burn out plaguing health care providers. The fact that cultural safety is becoming mandated across the region and increasingly embedded in current strategic planning speaks to budding transformations in health care delivery and points to an infusion of Nuuchahnulth worldviews about what healing is and how it should take place within biomedical structures.

I believe that this process is much larger in scope than the Nuuchahnulth nations alone, however they provide an exemplary case of how this is occurring. The NTC nursing services demonstrate how biomedical standards of practice can be adapted and moulded to provide care in a manner that is responsive to community expectations and needs. However, this requires an imperfect process of negotiating between community direction and systemic limitations such as defined scope of practice, implemented health targets, funding, available resources in remote communities (physical space, staff, and supplies), as well as the level of collaboration afforded by physicians and specialists serving the region. This process of negotiating and building to address community needs is ongoing at the Nuuchahnulth Tribal Council. For example, I was invited to attend a “meet and greet” event with physicians working in Campbell River. This event was intended to familiarize the doctors with the NTC Nursing Services, what they provide, and how to better collaborate. I was inspired to hear an NTC nursing manager explain to

the doctors how things are organized at the NTC. She stated, “if someone needs support, we pull together whatever resources we can and we create. We create something new. It’s how we work, how we’ve always had to work. If there is one person needing support then there is usually more” (field notes, April 30, 2019).

On an August day in 2019, one of my last days in the field, I found myself reflecting on Indigenous self-determination and health equity while taking my daughter swimming in the Somass River at Papermill Dam Beach, near the Tseshahat Reserve. The two of us sat in the sand and sifted pebbles. We placed them to float on small leaves and sent them down the gentle current. We watched the tidal river rise around us as we sat. I reflected that what is happening in current health policy in British Columbia could be likened to the Somass River. As a newcomer to the area, I was surprised to learn that the river is tidal. The Somass River, like all estuaries, exceeds definition as either a saltwater or freshwater body. Likewise, there are spaces in the health services serving the west coast that mimic estuaries. They are ecosystems where two different forces converge. Ecologically, estuaries are the most productive habitats due the nutrients provided through the mixing of salt and fresh waters. The river flowing out to sea waters down the salt of the estuary, but the tidal effect of the ocean remains profoundly transformative. And like the tidal effect in estuaries, the infiltration of Indigenous worldviews in health care reshapes the edges of existing structures and introduces new ecologies, shifting dominant perspectives on what it means to care and to heal.

Appendices

Appendix A Semi-structured Interview Guides

Interview Guide: Community Members

1. Have you seen a change in the way health care is provided over your life? How so?
2. Do you think people in your area ever have trouble accessing health care?
3. Can you tell me about an experience you have had receiving health care or treatment?
 - a. What was positive or negative about the experience?
 - b. How did this experience impact your overall health?
 - c. Is there anything you would have liked to have been done differently?
 - d. What did your care provider do to enhance your experience or wellness?
4. Can you compare your experiences receiving health care from NTC nurses to other health services?
5. What are some qualities that make a good health provider? Why are these qualities important?
6. Can you think of a time you were cared for, or you cared for someone else who was ill? What kind of life lessons have you learned about what it means to care for someone?
7. What are some Nuu-chah-nulth teachings about healing and wellness?
8. Do you think that Nuu-chah-nulth values and beliefs are respected through the NTC nursing?
9. Is it important for Nuu-chah-nulth communities to determine their own health care services?
10. Would you like to see more Nuu-chah-nulth traditions or healing practices encouraged in health care services? Why or why not?

11. Are there any other issues in the health care system you would like to speak about?

Interview Guide: Nurses and Health Leaders

1. What does a typical day at work look like for you?
2. How did you start working for the NTC nursing services?
3. What is unique about the NTC approach to nursing?
4. Can you tell me about how the NTC nursing services developed its approach to nursing?
5. Have you seen a change in the way nursing is done over the course of your career?
6. What do you enjoy most about your current profession? What do you find most challenging?
7. Do you think there are presently barriers for community members in accessing health care?
 - a. Why or why not?
8. Do you ever face barriers in providing health care?
 - a. E.g., time, lack of manpower, hard to reach populations, coordinating with other care providers
9. Can you tell me about an experience you've had treating a patient that left an impact on you (positive or negative)?
 - a. Can you describe the experience?
 - b. What was positive/negative about this experience?
 - c. What would you change about the experience if you could?
10. Can you tell me a bit about your experience adapting to nursing in Nuuchahnulth communities?
 - a. Did you experience a learning curve?
 - b. Did you ever feel like some of things you learned in nursing school were being challenged?
11. What characteristics define an excellent health care provider? Why are these important?
12. What does it mean to you to provide culturally safe care? Do you find this approach has an impact on your clients?
13. How are Nuuchahnulth values and beliefs acknowledged and respected through the nursing services?
 - a. Are there ever instances where nursing/medical norms clash with Nuuchahnulth culture/values or vice versa?
14. Would you like to see more Nuuchahnulth traditions or practices encouraged more in health care services? Why or why not?
15. Are there any issues (social, emotional, health) currently being neglected within your profession?

16. What kind of support for nurses and/or patients would you like to see more available?

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