

RELOCATING FOR SPECIALIZED CARE: EXPLORING FIRST NATION PATIENT
EXPERIENCES

by

Justice Seidel

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Indigenous Relations

The Faculty of Graduate Studies
Laurentian University
Sudbury, Ontario, Canada

© Justice Seidel, 2020

THESIS DEFENCE COMMITTEE/COMITÉ DE SOUTENANCE DE THÈSE
Laurentian University/Université Laurentienne
Faculty of Graduate Studies/Faculté des études supérieures

Title of Thesis Titre de la thèse	RELOCATING FOR SPECIALIZED CARE: EXPLORING FIRST NATION PATIENT EXPERIENCES	
Name of Candidate Nom du candidat	Seidel, Justice	
Degree Diplôme	Master of	
Department/Program Département/Programme	Indigenous Relations	Date of Defence Date de la soutenance August, 20 2020

APPROVED/APPROUVÉ

Thesis Examiners/Examineurs de thèse:

Dr. Jennifer Walker
(Supervisor/Directrice de thèse)

Dr. Daniel Cote
(Committee member/Membre du comité)

Dr. Pamela Toulouse
(Committee member/Membre du comité)

Dr. Lynn Lavallee
(External Examiner/Examineur externe)

Approved for the Faculty of Graduate Studies
Approuvé pour la Faculté des études supérieures
Dr. Serge Demers
Monsieur Serge Demers
Acting Dean, Faculty of Graduate Studies
Doyen intérimaire, Faculté des études supérieures

ACCESSIBILITY CLAUSE AND PERMISSION TO USE

I, **Justice Seidel**, hereby grant to Laurentian University and/or its agents the non-exclusive license to archive and make accessible my thesis, dissertation, or project report in whole or in part in all forms of media, now or for the duration of my copyright ownership. I retain all other ownership rights to the copyright of the thesis, dissertation or project report. I also reserve the right to use in future works (such as articles or books) all or part of this thesis, dissertation, or project report. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work or, in their absence, by the Head of the Department in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that this copy is being made available in this form by the authority of the copyright owner solely for the purpose of private study and research and may not be copied or reproduced except as permitted by the copyright laws without written authority from the copyright owner.

Abstract

This thesis explored the experiences of patients from the Moose Factory and Moosonee area who travel to larger urban cities for medical appointments. The main objectives of this project were to have a greater understanding of the patient experience in having to travel for medical appointments, as well as understand the strengths and challenges that patients face before, during, and after a trip to a larger city for a medical appointment. The study also provided participants an opportunity to envision approaches to improve patient experiences.

Through open-ended interviews with 10 participants, a number of themes were explored in relation to a patient's experience prior to attending an appointment, during an appointment, and returning home from an appointment. Most notably, the themes that were discussed in great length by many of the participants included issues with travel arrangements, transportation services, and food arrangements.

The results of this study were translated from patient experiences in travelling for medical appointments into recommendations that could be used by the local First Nation leadership to advocate for improvements to the healthcare system that affects their community members. These recommendations also are helpful to the local health authority that currently serves patients in the Moose Factory and Moosonee region.

Keywords: Moose Factory, Northern Ontario, medical transportation, patient experience, chronic diseases, health services.

Acknowledgments

This thesis would not have been possible without many important people in my life who constantly supported and inspired me throughout this journey. Firstly, I want to thank my supervisor, Dr. Jennifer Walker, for her constant encouragement and support throughout this entire process. She has been a main contributor to my positive experience in pursuing a Master's degree and I'm so grateful for her advice, kindness and friendship throughout this chapter in my life. A big meegwetch to my committee members, Dr. Pamela Toulouse and Dr. Daniel Cote, for their time, support, and thoughtful contributions to this project.

I would also like to sincerely thank Christina Linklater at the Moose Cree Health Center who shared helpful feedback and advice, and who advocated for community approval for the project.

Meegwetch to the Weeneebayko Area Health Authority for funding the project, which allowed me to travel to Moose Factory to conduct all stages of the research face-to-face in the community. Another meegwetch to the Moose Cree Education Authority for funding my education throughout my post-secondary studies.

A big thank you to my aunts, uncles, cousins and friends who were always available to talk through all my thoughts on this topic before I was ever interested in pursuing a Master's degree. A special thank you to my aunties Sharon, Betty, and my cousin Dana who are always there for me and who always shared their love and support throughout this experience. To my MIR bestie, Julia, who spent many days and nights by my side writing and bouncing ideas off one another.

I wouldn't be the person I am today without my parents, who always believe in me and have given me the tools to succeed through all my endeavours. I also would have never been

able to accomplish this without my siblings, Dylan, Kiana, and Ty. Our close relationship kept me grounded throughout this journey and I'm so grateful for the laughter we always share together.

To my grandmothers, Joan and Beulah, who are two rays of sunshine in my life.

To my angel, my late grandpa Abel Butterfly, who sadly passed away while I was in the process of writing this thesis. I'm so grateful for the years and experiences we shared with one another, and for all of his stories and teachings that have shaped my life. This wouldn't exist without you.

Finally, a huge thank you to the participants who were involved in this project. I am forever grateful for their participation in this project, and I admire the courage and strength they showed in sharing their experiences with me. Meegwetch.

Table of Contents

Abstract	iii
Acknowledgments	iv
Table of Contents	vi
List of Tables	ix
List of Figures	x
List of Appendices	xi
Preparing for the Canoe Trip (Situating Self)	xii
Chapter 1 : Introduction	1
1.1 Understanding the Situation	1
1.2 Medical Travel Process in Moose Factory/Moosonee	2
1.3 Outward Looking (Study Rationale)	7
1.4 Terminology	8
1.5 A Note on Framework	9
1.6 Chapter Summary	13
Chapter 2 : A Survey of the Landscape (Literature Review)	14
2.1 Colonialism and Health	14
2.2 Displacement for Health Care	16
2.3 Jurisdictional Issues	18
2.3.1 Federal Responsibility	19
2.3.2 Provincial Responsibility	20
2.3.3 Local/Community Responsibility	21
2.4 Chapter Summary	23
Chapter 3 : Deciding What is Needed for the Journey (Theoretical Framework)	24
3.1 Decolonizing Methodology	24
3.2 Community-Based Participatory Research	25
3.3 Community Engagement	26
3.4 Chapter Summary	27
Chapter 4 : Gathering Tools (Methods)	29
4.1 Research Design	29
4.2 Qualitative Methods	29
4.3 Recommendations from Community Partners	30
4.4 Ethics & Community Approvals	30
4.5 Recruitment of Participants	31

4.6	Shoving off the Shoreline and Leaving Camp (Methods of Data Collection)	33
4.7	Description of Participants	34
4.8	Patterns of Stories and Interviews (Data Analysis)	35
4.8.1	Coding	36
4.8.2	Participant Check-Ins	37
4.9	Evaluating Qualitative Research	38
4.9.1	Prolonged Engagement for Thick, Rich Data	39
4.9.2	Member Checking	40
4.10	Chapter Summary	40
Chapter 5 : Feeding on Northern Foods of Wisdom for Survival (Results)		42
5.1	Participant Experiences Preparing for an Appointment	44
5.1.1	Issues with Local Health System	44
5.1.2	Issues with Policies	45
5.1.3	Personal Preparation for Out of Town Appointments	48
5.2	Travelling and During an Appointment	48
5.2.1	Issues with Travel Arrangements	49
5.2.2	Issues with Transportation Services	51
5.2.3	Issues with Food Arrangements	53
5.2.4	Experience with Doctors or Healthcare Workers During Appointment	55
5.3	Looking Back/Reflecting	56
5.3.1	Acknowledging privilege	56
5.3.2	Support	57
5.3.3	Self-Advocating	57
5.4	Positive Aspects of Travelling for Medical Appointments	58
5.5	Suggestions for Improvement from Participants	59
Chapter 6 : Bringing it All Together (Discussion)		62
6.1	Preparing for an Appointment	62
6.2	Travelling and During an Appointment	66
6.3	Looking Back & Reflecting	69
6.4	Recommendations for Improvements	71
Chapter 7 : Final Reflections & Conclusion		75
7.1	Navigating Through Rough Terrain (Limitations of the Study & Further Research)	76
7.2	Celebration of the Research Journey (Strengths of the Study)	77
Chapter 8 : References		78

List of Tables

Table 1 - Age Distribution of Participants	34
Table 2 - Thematic Analysis Process	36

List of Figures

Figure 1 – Personal Photograph of my Late Grandpa and I	xiv
Figure 2 – A Patient’s Journey for Medical Travel	3
Figure 3 – Overview of Framework	10
Figure 4 – Overview of Themes	43

List of Appendices

Appendix A – Community Approval	88
Appendix B – Recruitment Poster	89
Appendix C – Letter of Information	90
Appendix D – Consent Form	92
Appendix E – Semi-Structured Interview Guide	93

Preparing for the Canoe Trip (Situating Self)

“Prior to the trip, there is an inward looking and a lot of self-reflection... We examine self in relation with others, self in relation with community, and self in relation with the natural world... It is from this inner core we travel and spiral outward in a relational way as we think about key research questions to issues and challenges we face in our families and communities.”
(Michell, 2012, p.3)

As an Indigenous researcher, it is important for me to situate myself within this research in order to provide readers with a greater understanding of my experiences and connections to the research that will be explored throughout this thesis.

I first introduce myself as a Cree woman from Moose Factory Island, Ontario, Canada and a member of the Moose Cree First Nation. Moose Factory is a small island along the western coast of James Bay. I grew up in my community for a portion of my childhood, learning various traditions and aspects of my Cree culture from my grandparents, aunts, uncles and close family friends. My immediate family and I moved from Moose Factory to the small town of Espanola in Northeastern Ontario where my parents had both found jobs and to be closer to my father’s family of mixed European descent. From Espanola, my family and I moved to Sudbury for my older brother to pursue a competitive hockey career and, ever since, have resided in the city of Sudbury. I often find myself explaining my current living situation as going to school and working in Sudbury. Over the years I have created a great community of friends and family who live in the city, and a large part of my life has taken place in this city, but to me, my true home and heart belongs in Moose Factory.

I personally believe that I have been extremely fortunate to have had the opportunity to obtain an education in an urban area from the beginning of my education journey. I was able to attend a French-immersion school that I believed challenged me throughout my formative years in school. Having been immersed in the Western education system, I feel as though I was able to

have a duality of knowledge in Western society, but also in my own cultural Cree society. Although at times in my childhood this duality left me with confused and mixed feelings with my identity, as an adult I have been able to find security and comfort in my identity as a Cree woman with urban roots. While this way of life has provided me with numerous positive experiences, skills and opportunities, I have also experienced many negative emotions from this dual identity. I choose to use the skills and privilege I carry by seeing through both a Western and Cree lens to better advocate and support voices who are not often heard (Bartlett, Marshall & Marshall, 2012).

While I attended school in urban cities for the entirety of my education from kindergarten to university-level, I have always remained deep-rooted in my home, and have always spent my summers and breaks off school in Moose Factory. Coming from an extremely large extended family, I have always been surrounded and supported by family in every stage and part of my life. Family has always been an integral part of my upbringing, especially the presence of my grandparents. From a very young age, my grandparents have meant the world to me, as many grandchildren view their grandparents. For me, I have always felt a sense of pride in my grandparents, not only due to the fact that they are amazing people, teachers and storytellers, but because of the strong family unit they built and brought their children and grandchildren into.

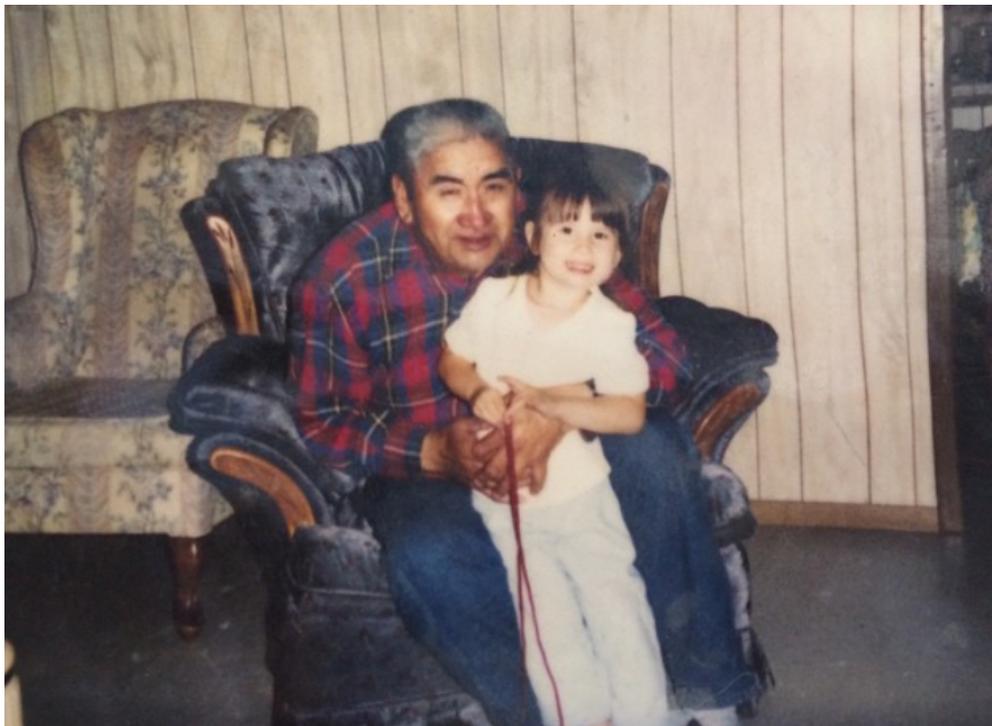
My grandparents, Beulah and Abel Butterfly experienced colonization in two very different ways. Like many First Nations children, my granny was forced into a residential school at the age of 6. She attended the Bishop Horden Memorial School for the majority of her childhood years where she was subjected to much of the abuse that is well-documented within residential schools. My grandpa's family was able to flee from ministers and government officials forcing children into residential schools. He and his parents found refuge deep in the

bush and lived on the land for many years. Through years of abuse, hurt and pain at the hands of the Canadian government, both my grandparents were able to persist and build a better life of their own, and the generations that exist because of them are testaments to their strength and resilience.

I choose to introduce my grandparents to situate myself in my own research, because without the years of courage and bravery, I would not be here to complete this research. Much like they cared and watched over me for so many years, I feel a sense of responsibility to do the same for them as years go by and my grandparents reach the elderly ages of their lives. My research topic came to me, years before I was ever considering a Master's program, but from a personal experience that occurred while attending a medical appointment with my grandpa.

Figure 1

Personal photograph of my late grandpa and I



Living in a remote community, it is difficult to obtain access to a number of quality services, health care being one of them. In Moose Factory, we are one of the fortunate communities along the coast of James Bay that has a hospital equipped to treat patients with every day medical needs. However, if patients require more specialized care or services, patients must travel to urban hospitals in order to receive the necessary medical care they need. This was the case for my grandpa, who suffered with diabetes and accidentally cut one of his toes while completing yard work. His injury had been noted and looked at by doctors in the community, however healing had not taken place and his toes began showing signs of gangrene. As doctors noticed this, he was referred to see a surgeon in Kingston, Ontario to determine the next steps for his medical issue. At the time, I had been spending the summer at my grandparent's house, and in a last-minute family emergency took the responsibility to be his escort for his appointment.

Together, we travelled by chartered flight from Moosonee to Kingston and stayed in the local hostel together until his appointment. On the day of the appointment, my urban Cree identity allowed me to feel very confident in the hospital setting in Kingston. I had been to various hospitals in urban cities before, and understood the ways of directories and maps, which is much different than that of our hospital on the reserve. That morning, my grandpa and I arrived at the hospital, much bigger and complex than the one my grandfather was used to. I guided him to the appropriate wing of the hospital, helped him check in, and waited with him to be called to see his doctor. When we were let into a room and introduced to the doctor, I noticed quite a few issues in the interaction between my grandfather and the doctor treating him. One of the most obvious barriers in their contact was language. Speaking mainly Cree, my grandpa had difficulty communicating in English with the doctor to answer basic questions about his medical history. Acting as an interpreter, I helped my grandpa to answer the questions and explained

some of what the doctor was trying to ask. Another component of language that presented itself as difficult was the vocabulary and medical terms used by the doctor. Having finished a science-related degree and having interest in health and medicine, I was able to understand and comprehend the details of my grandfather's condition. My grandfather, however, had never been accustomed to these terms and needed explanation of his condition in terms and words that he could make sense of. The end of the appointment neared, and my grandfather was admitted to the hospital for further tests before the surgery. After the appointment, I had time to reflect and I had many concerns and questions. What if I was not there to help my grandfather with answering and understanding questions? Are there Cree interpreters or known community members to support and help in these situations? What if my grandfather agreed to terms or answered questions incorrectly due to the fact that he couldn't understand or hear properly? From this experience, I was concerned for my grandparents and their experience when they travelled for medical appointments.

It was also during the experience in travelling for the appointment that I realized there were many challenges faced when my grandpa and I travelled for his medical appointment. I felt this research topic was an important one to me, as I could clearly see how medical travel and out of town appointments affect my beloved family members. This research topic also felt important in the community, as there were many discussions occurring in the community regarding community healthcare, the medical travel process, and approaches to provide better experiences to community members. It is my hope that this project can provide results to the local political structures to understand patient experiences, so they are taken into consideration during policy changes or development.

Chapter 1 : Introduction

1.1 Understanding the Situation

Many First Nation (FN) communities in rural or remote parts of Canada do not have specialized health services in their community for community members to access (Lavoie et al., 2015). Instead, FN patients must leave their community and travel to larger, urban hospitals to access general practitioners, specialists, dialysis, or other health services depending on their health condition. In some cases, relocation may be permanent (end-of-life care, dialysis, personal preference); in other cases, it may be a single event or appointment, and patients may return to their community. There is a growing body of literature that has documented the negative psychosocial effects that medical transfers have on Indigenous patients (Salvalaggio et al., 2003, Kornelsen et al., 2011; Lavoie et al., 2015; McKenzie, 2015; Zacharias et al., 2011). These studies have found that logistics, funding, social and cultural supports, and support for escorts and family members are inadequate (Salvalaggio et al., 2003, Kornelsen et al., 2011; Lavoie et al., 2015; McKenzie, 2015; Zacharias et al., 2011). These issues arise due to the diverse federal, provincial, regional health authorities, hospital and FN policies that may apply at different times in a medical relocation, making it difficult and frustrating for patients to navigate the health system and medical relocations (Lavoie et al., 2015).

With the rapid increase of chronic diseases (diabetes, arthritis, heart diseases, COPD, dementia, etc.) at much younger ages, many FN patients are requiring more advanced and specialized medical care than what is available in their community (Reading, 2009; Bruce et al., 2014). Thus, more patients are requiring medical transfers to larger, urban hospitals to receive health care. Despite improved services in many cases, Indigenous patients seeking care outside of their community may experience culturally unsafe care, racism, discrimination and

stereotyping from service providers, reinforcing historical colonial relationships (Jacklin et al., 2015).

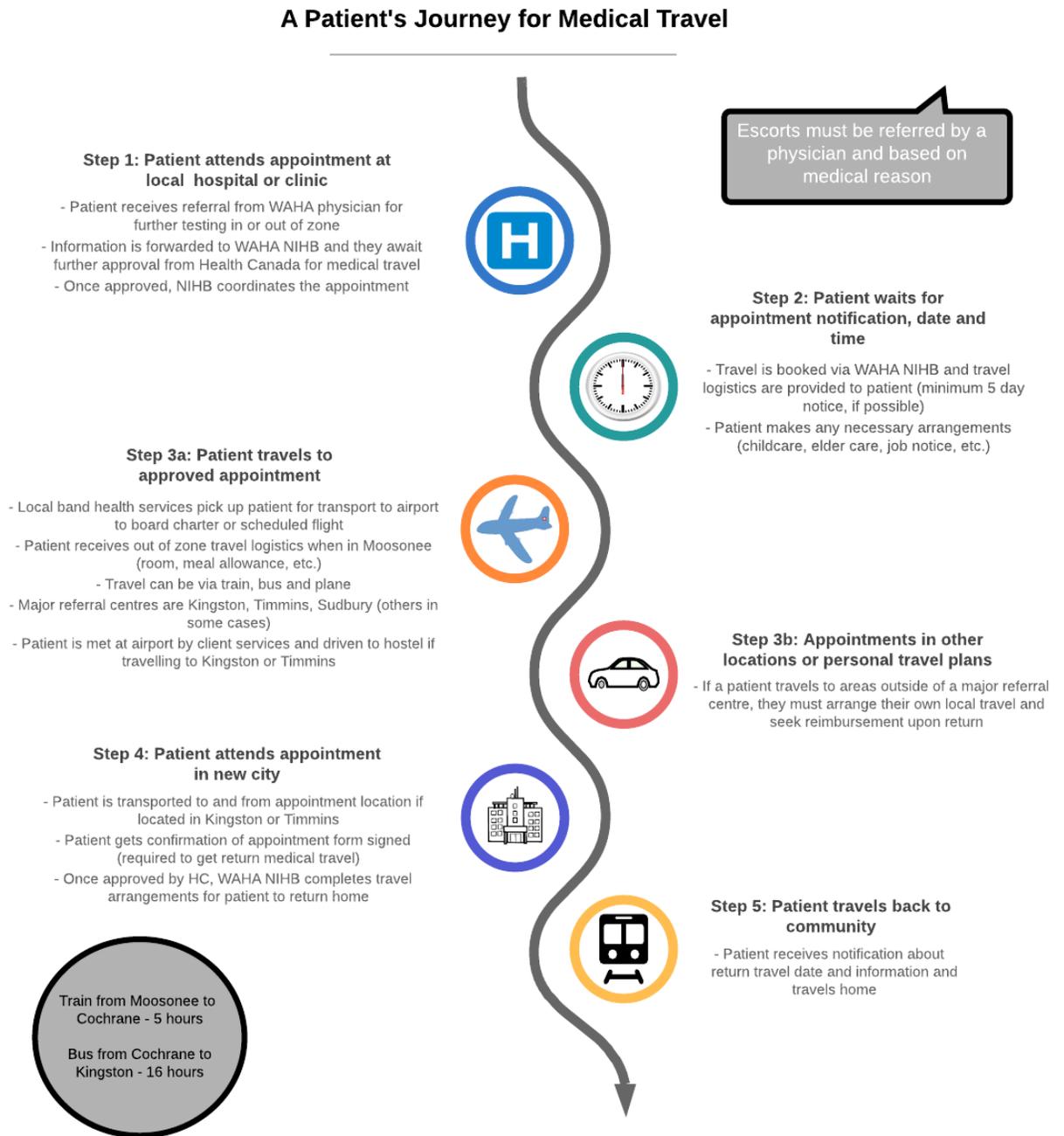
FN patients from the Weeneebayko area (James and Hudson Bay lowlands) receive health services from the local health authority, Weeneebayko Area Health Authority (WAHA). WAHA is one of two health authorities in Ontario that is completely First Nations governed and thus plays a unique role in providing health services to the communities and people of the Weeneebayko region (WAHA, 2019). These include patients from the Moose Cree FN, Fort Albany FN, Attawapiskat FN, Weenusk FN, and the Kashechewan FN. Patients from the Moose Cree FN can access local health services at the Weeneebayko General Hospital (WGH), located on the island of Moose Factory, which provides acute and chronic care, 24-hour emergency services, and family medicine clinics (WAHA, 2018). Other services by the WGH include occupational and rehabilitative services, general surgery and anesthesia, a traditional healing program, and a regional mental health program (WAHA, 2018). Patients who require emergency or specialized medical treatment are referred to receive tertiary care beyond the WAHA area and are primarily transferred to the Kingston General Hospital and the Timmins District Hospital (WAHA, 2018).

1.2 Medical Travel Process in Moose Factory/Moosonee

Medical travel from remote isolated communities is complex and requires multiple steps and organizational processes in order for patients to travel from their community to a larger urban hospital. Figure 2 (page 19) provides a visual overview of this process for patients from the Moose Factory/Moosonee area.

Figure 2

A Patient's Journey for Medical Travel



In order to initiate the medical travel process, patients must attend an appointment at the local hospital in Moose Factory, Ontario or at the local clinic in Moosonee, Ontario. At this appointment, patients receive a referral from their physician describing the need for further testing out of zone (NIHB Working Group, 2013). If a patient requires a non-medical escort for their appointment, this must be referred and supported by the physician and is approved by the First Nation and Inuit Health Benefit (FNIHB) program based on medical reason. If approved, non-medical escorts are chosen by the patient to provide them with support while they attend their appointment out of town. Escorts are approved by FNIHB when there is a legal or medical requirement that results in the patient being unable to travel alone (Government of Canada, 2020). For example, patients eligible for an escort include: patients under the age of 18, patients that require alternative legal consent or decision making, patients that require assistance with activities of daily living, those who face language barriers, patients undergoing medical procedures, patients who have a medical condition that result in assistance during trip, or if a pregnant women is travelling to give childbirth (Government of Canada, 2020).

The information provided by the physician during this initial appointment is forwarded to the WAHA Non-Insured Health Benefits (NIHB) department, where they await approval from Health Canada for medical travel (NIHB Working Group, 2013). If the referral is approved by Health Canada, the WAHA NIHB department then coordinates an appointment for the patient.

Next, patients await an appointment notification from the WAHA NIHB department for an appointment date and time. Patients must confirm their appointment time 5-10 days prior to the appointment time (NIHB Working Group, 2013). After patient confirmation, WAHA NIHB department books the patient's travel and provides travel logistics to the patient. Once a patient's travel is booked, the patient may need to make any familial arrangements in order to travel out of

the community. These may include childcare or elder care arrangements, informing their employer, getting approval from their employer, pack for their trip, and other personal considerations.

On the day of a patient's travel, the local band health services will pick up a patient for transport to the local airport or train station in Moosonee (NIHB Working Group, 2013). This transportation looks different during each season. During the summer months, a charter boat transports patients to the Moosonee docks. From there, another local band health service will provide transportation from the Moosonee docks to the Moosonee airport or train station. In the winter months, the local ice road from Moose Factory to Moosonee is used to transport patients between the communities. During break up and freeze up season, when the river is unsafe to travel on, helicopter transportation is used to transport patients to their airport or train station in Moosonee. Once the patient arrives at the airport or train station in Moosonee, they will receive more travel logistics for the place they are travelling to for their appointment. This information includes the place where they are staying and meal allowance tickets (NIHB Working Group, 2013).

Patients travel from Moosonee by plane, or by train and bus to one of the major referral centers for WAHA. These referral centers include Kingston and Timmins. If a patient arrives in Timmins or Kingston by plane, they are met at the airport by client services and are driven to their hostel or hotel room that they will be staying in while they are in a new town for their appointment (NIHB Working Group, 2013).

On the day of the patient's appointment, local transportation is provided to and from the appointment location from the patient's hotel or hostel (NIHB Working Group, 2013). Patients are dropped off at the appointment location and are expected to attend their appointment. During

the appointment, patients are required to get a confirmation of appointment form signed by the physician in order for their return travel to be booked (NIHB Working Group, 2013). Once this form is approved, the WAHA NIHB department can then complete return travel arrangements for patients. Patients then follow the similar process in travel to return home from their appointment.

Depending on the type of medical treatment needed, and the timing of the trip, patients are required to leave their community and may stay in these urban areas for as little as a few days to as long as a few months. Studies that have examined the effects of medical relocation in moving Indigenous patients out of their communities to larger urban cities have found that medical relocation occurs at great financial and emotional cost and disrupts the continuum of care for Indigenous patients (Bartlett et al., 2007).

While no policies exist describing WAHA's specific commitments to patients being primarily transferred to KGH and TDH, it has been stated that KGH has had a longstanding program providing service to residents of the WAHA catchment area (HayGroup, 2016). Due to the distance a patient must travel to KGH from their home community in Northern Ontario, this partnership does not present itself as being effective for patients. The geographical differences between Southern and Northern Ontario may be difficult for patients from remote, First Nation communities in the North to navigate. Thus, a main referral centre in the North may improve be effective in treating patient's that WAHA serves.

In additional, medical schools located in the North, such as the Northern Ontario School of Medicine, are committed to providing socially accountable service to the needs and the diversity of populations in Northern Ontario, including Indigenous, remote, rural and underserved communities (Northern Ontario School of Medicine, 2020). The training of future

socially accountable physicians, located in the North and aimed to serve the North present itself as a better partnership opportunity for WAHA to engage with.

1.3 Outward Looking (Study Rationale)

“You learn how to read the land for survival, looking for key patterns in the studies. What hunters have passed through the area before? What might the footprints tell us of past events and happenings? Pay attention to identity gaps in the literature and to critiques to allow for a balance of perspectives. Articulate a rationale for why you are embarking on a research journey based on those gaps. What makes your research different?” (Michell, 2012, p.5)

Travelling for medical appointments will likely remain to be a reality for FN patients throughout Canada, due to diverse geographic regions and inadequate funding (Lavoie et al., 2010). However, FNs, local hospitals, and regional health authorities can respond to the needs of community members through improved policymaking for medical transfers, thus leading to improved patient experiences. This project will translate patient experiences into recommendations for policy improvement to allow for patients from the Moose Cree area to have improved experiences through the medical travel process.

The objectives of this project are to understand the experiences of patients when they travel for medical appointments in urban cities, understand the challenges and strengths that come with medical travel, envision approaches to improve patient experiences and to provide local leadership with recommendations in improving patient experiences. The MCFN leadership and community have expressed the need to further understand the health services and improve health service delivery in the community. This research will respond to those concerns and provide more information on the strengths and challenges that MCFN patients face when they travel for medical appointments. In identifying challenges and issues that patients face, possible solutions and recommendations to the FN, hospital, or local health authority can be made to mitigate these issues. This research will add to the growing body of research being completed

with Indigenous communities to have more insight on FN health and the needs of FN patients. It will also add to the literature that uses community-based approaches in research.

Through my preliminary reading and literature review, I found the stories and experiences of patients were rarely discussed or considered. In addition, I found little to no literature that focused on the situation within the FN communities along the James Bay. It was important to me and to my community partners to ensure that the voices of community members were heard through the research project to provide important context to issues relating to medical travel that were being identified in the community.

The approach I used to accomplish these objectives were determined in a collaborative manner between myself and members of the Moose Cree Health Centre. I recruited 10 community members from the Moose Factory and Moosonee area to participate in a one-on-one, face-to-face interview in which participants described their experience prior, during, and after an appointment out of town. Participants also shared their thoughts relating to positive and negative aspects about travelling for medical appointments and were also able to reflect on ways in which their experience could be improved.

1.4 Terminology

It is important to clarify terminology as the terms Indigenous, First Nations (FN), Inuit, and Métis are used throughout the writing. Within the context of this thesis, Indigenous is to mean: “an inclusive and international term to describe individuals and collectives who consider themselves as being related to and/or having historical continuity with “First Peoples”, whose civilizations in what is now known as Canada” (Allan & Smylie, 2015). Thus, the term Indigenous is used to describe the collective groups of First Nations, Inuit and Métis people in Canada.

I also want to acknowledge the distinct terms of FN, Inuit and Métis as they each describe a unique and different group of Indigenous peoples in Canada. Within this study, the research involved the participation of FN people, specifically those from the Moose Factory and Moosonee region, also known as the Moose Cree area. First Nation in this context refers to people who are recognized as members of a FN community as defined by the Indian Act (Allan & Smylie, 2015). This project aims to recruit participants who travel for medical appointments, which is covered by the FNIHB program through Health Canada. Patients must have First Nation status in order to receive benefits from this program, which is why this project is using Health Canada's definition of status FN. There are times throughout the writing where the term Cree or Moose Cree is used to specifically describe the FN people from the geographical region of Moose Factory or Moosonee, Ontario or people from the Moose Cree FN (MCFN).

1.5 A Note on Framework

This thesis is formatted in a way that diverts from Western research titles and instead is centered around Herman Michell's (2012) metaphor that doing community-based research is like going on a canoe trip to hunt for knowledge. Within this metaphor, Michell (2012) uses a Cree worldview to describe each step of the research process in a way that aligns with my Cree teachings and values. Following each section title, a short excerpt from Michell's (2012) metaphor is shared to provide a greater understanding of the section to be discussed. Figure 3 (page 26-28) details the framework used in this study. This framework of my thesis caused me to constantly reflect on my core teachings and values throughout the research process. I believe this resulted in a research project and report that was authentic and meaningful to me as a researcher and a community member.

Figure 3

Overview of Framework

Preparing for a Canoe Trip (Research Journey)

Adapted from *The Canoe Trip: A Northern Cree Metaphor for Conducting Research* by Herman Michell (2012)

Preparing for the Canoe Trip (Situating Self)

"Prior to the trip, there is an inward looking and a lot of self-reflection... We examine self in relation with others, self in relation with community, and self in relation with the natural world... It is from this inner core we travel and spiral outward in a relational way as we think about key research questions to issues and challenges we face in our families and communities." (Michell, 2012, p.3)

Outward Looking (Study Rationale)

"You learn how to read the land for survival, looking for key patterns in the studies. What hunters have passed through the area before? What might the footprints tell us of past events and happenings? Pay attention to identity gaps in the literature and to critiques to allow for a balance of perspectives. Articulate a rationale for why you are embarking on a research journey based on those gaps. What makes your research different?" (Michell, 2012, p.5)

A Survey of the Landscape (Literature Review)

"Doing a literature review is like surveying the hunting territory in order to have a general idea of the discourse that lies in this path. You see the animal tracks and pursue where they lead. Sometimes they lead nowhere. Other times they lead you directly to the source. You learn how to read the land for survival, looking for key patterns in the studies." (Michell, 2012, p.5)

Deciding What is Needed for the Research Journey (Theoretical Framework)



"Hunters often share stories of their past experiences in particular areas. They help us to think about what we may need on the trip and what to expect... How we see the world is important. The way we think about knowledge is different in different cultures. A strategy of inquiry or a research plan is like a map that helps one arrive at different camps along the way." (Michell, 2012, p.4)



Gathering Tools (Methods)

"The methods are the actual tools that will help you answer the research questions posed and allow you to arrive at your final destination... Using traditional protocols allows a researcher to conduct a study in a good way... Our Cree ethics of conservation teaches that we only take what we need and nothing more" (Michell, 2012, p.5-6)



Shoving off the Shoreline and Leaving Camp (Data Collection)

"Finally, we quietly shove off from the shores of our camp. The research process commences. There is rhythm in the paddling, momentum, and energies are high with enthusiasm. Eagles soar in the sky and remind us that we must look far into the past and far into the future. We meet and listen to travellers who have been placed in our path, paying attention to the nuances. We learn to read between the lines. There are hidden teachings in Cree words. We share in reciprocity." (Michell, 2012, p.5)



Patterns of Stories and Interviews (Data Analysis)



"In the data analysis phase, we look at the overall pattern of messages. What are voices telling us? We see the saturation of data, a signal it is time to bring the journey to a close." (Michell, 2012, p.6)



Resting at Campsites of Knowledge and Wisdom (Results)

"We shove off from the shores and head for our final destination. The paddles are once again in unison...We are grounded and focused on the incredible diversity of perspectives. Like the boreal forest trees, we honor and respect the different shapes, sizes, colours, and "rooted-ness...The voices of research participants speak through you. What you write reflects the landscape of where those voices originate." (Michell, 2012, p.6)





Transformation and What Other's Don't See (Discussion)



"The editing process will take the research team through winding rivers, small streams, deep reflection in ponds, and down tight corridors that refine and polish what has been written. We look at our emerging and collective knowledge. Did we cover everything that needs to be told? Has the initial research question been answered? What have we learned? We see things other people do not see." (Michell, 2012, p.7)



Navigating Through Rough Terrain (Limitations & Future Studies)

"Factor in flexibility for unexpected twists and turns of the research journey. Embrace the ambivalence and flux as the weather can change, the river waters may become tumultuous, and the terrain may be rugged, making for slow travel. It is during these times that great learning takes place. Things always happen for a reason. Lessons learned are documented along with challenges encountered by using the research design." (Michell, 2012, p.5)



Celebration of the Research Journey (Strengths)

"We look across the vast lake and to our final destination. The dark clouds begin to recede and there is a heavy smell of earth and soil in the air. We breathe it in deeply, Spirit touching where we need healing. We paddle away in fervour. Our families on the shoreline are waving and patiently waiting." (Michell, 2012, p. 7)



1.6 Chapter Summary

Members of the MCFN with health conditions that require specialized health services not available in the community must travel to larger urban cities for medical appointments. The process in which they get approved and travel for an out of town appointment is outlined as the medical transportation, a lengthy process requiring numerous steps and approvals from different levels. Due to the remote nature of the MCFN community, having to travel for medical services will likely remain a reality for many community members. Thus, it is imperative that the perspective and experience of patients' travelling to larger cities for medical care are understood and heard in order to address any concerns or issues that may be taking place. This study aims to better understand the patient experience in having to travel for medical care outside of the community through qualitative semi-structured interviews in which patients share their experiences prior, during, and after a medical appointment in a larger urban city. The challenges and strengths of travelling for medical appointments will also be explored. The results from this study will be used to inform local health leadership of the experience of patient's while they travel to appointments outside of their community and envision approaches to policy improvement. In the next chapter, a thorough examination of current literature related to the realities of health systems in FN communities is covered.

Chapter 2 : A Survey of the Landscape (Literature Review)

“Doing a literature review is like surveying the hunting territory in order to have a general idea of the discourse that lies in this path. You see the animal tracks and pursue where they lead. Sometimes they lead nowhere. Other times they lead you directly to the source. You learn how to read the land for survival, looking for key patterns in the studies.” (Michell, 2012, p.5)

2.1 Colonialism and Health

In Canada, during the post-Confederation era original inhabitants of the land were physically displaced from traditional territories and were forced to live on reserve land. The creation of reserve lands reflects the longstanding history of domination and early attempts to assimilate Indigenous peoples of Canada (Adelson, 2005). Reserve land was set aside for the use of registered Indians with the legal title to the land held by the Crown (Richmond & Ross, 2009). Reserve land was often marginal, meaning it did not support Indigenous lifestyles of traditional hunting, fishing, and gathering or economic activities such as farming and were often situated in isolated locations to be removed from the non-Indigenous population (Richmond & Ross, 2009). Within an Indigenous worldview, the land is central to Indigenous culture and ways of being and plays a fundamental role in the health and wellness of Indigenous communities (Richmond & Ross, 2009). Thus, the physical displacement of Indigenous communities from traditional lands and territories has negatively affected the collective wellbeing of Indigenous communities in Canada and across the world (Richmond & Ross, 2009). Notable scholars argue that the loss of land has largely contributed to the cultural stress experienced by Indigenous communities throughout Canada (Bartlett et al., 2007; Adelson, 2005; Richmond & Ross, 2009).

In addition to the establishment of the reserve system, Canada also adopted the Indian Act of 1876, which established First Nations as wards of the state (Lavoie et al., 2010). The introduction of the Indian Act caused Indigenous communities to be displaced socially and

culturally through colonial policies that aimed to erase their cultural values, customs and beliefs (Aboriginal Affairs and Northern Development Canada, 2011). For example, amendments to the Indian Act banned specific traditional ceremonies and gatherings, which resulted in many being pushed underground and some practices being lost for generations (Adams, 1995). Specifically, in the Moose Cree region, numerous groups of Christian missionaries began establishing religious places of worship in Moose Factory, starting in 1672 and continue today (Reimer & Chartrand, 2005). Presently, there is a strong following of Christian religion that exists in the Moose Factory community (Lacasse, 2017).

Additionally, the residential school era arose through educational policies that were aimed to assimilate Indigenous children. Children were forcibly removed from their homes, were forbidden the use of their traditional language, teachings, or culture and were subjected to much emotional, mental, physical and sexual abuse (Bombay et al., 2014). These colonial activities undermined the social and cultural pillars that are central to Indigenous identity, as they prohibited families from sharing the cultural practices that tied Indigenous peoples to their traditional land, practices and culture (Richmond & Ross, 2009). The result of hundreds of years of colonization and colonial policies are argued to be the main contributor resulting in the poor health and wellbeing of Indigenous peoples in Canada (TRC, 2015).

Indigenous peoples in Canada have a higher risk of developing multiple chronic conditions (MCC) due to the intergenerational trauma from colonization and the health inequities that exist in FN communities (Reading, 2009). Chronic diseases (diabetes, arthritis, heart diseases, COPD, dementia, etc.) have become epidemic among FN peoples in Canada and are occurring at younger ages compared to the rest of the population (First Nations Information Governance Centre, 2018). Over the last 50 years, the incidence of chronic conditions within FN

populations have been steadily increasing (Bruce et al., 2014). Having two or more chronic conditions is often referred to as multiple chronic conditions (MCC) and is a main driver for developing numerous disabilities (Reading, 2009). Studies show that Indigenous individuals aged 55- 64 report three or more chronic conditions, resulting in rates that are 3.5 times higher than the non-Indigenous population (Bruce et al., 2014). FNs are further complicated by the challenges of accessing quality health care services in remote and northern communities due to the ongoing colonial relationship that many FNs have with the federal government (Reading, 2009). As the incidence of MCC increases in Indigenous populations at much younger ages, it is inevitable that we will see an increase in travelling for medical appointments that will occur to ensure Indigenous peoples are receiving adequate care for their health issues.

2.2 Displacement for Health Care

Indigenous patients from many rural and remote communities must leave their communities to receive mainstream medical services that are not available where they live. This process is known as medical travel, where patients are transferred to larger, urban hospitals, to access general practitioners, specialists, dialysis, or other specialized health services (Lavoie et al., 2015). In some cases, the relocation may be permanent in the event of end-of-life care, dialysis, or simply personal preference. In other cases, the relocation may be a result of appointment and patients may return to their community in as little as a few days. While medical travel allows for greater medical services, there exist many cultural, mental and emotional issues with medical relocations. The lack of cultural and social support through medical relocations, unfamiliar settings, and the deeply ingrained racism that Indigenous patients experience result in many Indigenous patients having negative experiences with medical relocations (Kornelsen et al., 2003; Adelson, 2005; Marrone, 2007). Some argue this is due to the fact that healthcare has

been shaped by a century of internal colonial politics that have effectively marginalized Indigenous people from the dominant system of care (Adelson, 2005).

There exist many health conditions and cases in which Indigenous patients across Canada are transferred to a larger hospital. For example, in Nunavut, 53% of patients needing inpatient and outpatient hospital care are transported outside of the territory (Canadian Institute for Health Information, 2010). An examination of the medical transfer system in Nunavut found that the psychosocial needs of Inuit patients and their families are not being met, causing direct negative effects on patient mental health and their medical outcomes (McKenzie, 2015).

In rural or remote communities, pregnant Indigenous women are often transferred to urban hospitals near the time of their delivery to give birth at larger hospitals (Kornelsen et al., 2011). Several studies have examined the social and emotional effects of relocation for birthing and have found that Indigenous women in referral centers often do not receive adequate emotional or labour support when their partners and families cannot accompany them (Couchie & Sanderson, 2007; Chamberlain & Barclay, 2000). Furthermore, a birthing women's community also experiences negative effects from the relocation of birth, causing strain on the woman's family left behind, and communities feeling a collective sense of loss of a family and community event in the life cycle (Wilson, 2003).

There have also been devastating stories of patients losing their lives during their relocation to a larger hospital, such as that of Abraham Donkey, a resident of Nelson House, Manitoba. Mr. Donkey was travelling 650 kilometers from Thompson, Manitoba for an appointment at Winnipeg's St. Boniface Hospital. During his 9-hour bus ride to the hospital, Mr. Donkey died on route as he travelled for a follow-up appointment with his doctor after having

stents put in his heart (CBC News, 2017). This situation has prompted a call for an inquiry into whether the province could have done something differently.

The experiences of patients who must leave their communities and relocate to larger, urban centres to receive permanent dialysis have also been explored. Results from these studies highlight that physical symptoms, loss of independence, altered interactions with family and friends, and psychosocial adaptation to illness were common among dialysis patients who were relocated from their community for care (Salvalaggio et al., 2003). Moreover, patient concerns relating to increased expenses, housing inadequacies, family separation and a lack of control over health care decisions are also felt while in urban cities for prolonged stays during dialysis treatment (Zacharias et al., 2011).

Although the relocation of rural and remote First Nations peoples to referral centers provides them with increased access to specialized services, the quality of care they often receive often does not match the level of physical and emotional support found in their home communities (Kornelson et al., 2011). Due to the limited health services in small rural communities, local specialized health services for First Nations communities are not feasible. Solutions are needed to mitigate the stress of relocation for medical treatment and to involve communities in the decision-making process.

2.3 Jurisdictional Issues

Numerous studies have recorded the patient experience in medical relocation and found it difficult or frustrating for patients to navigate the health system and medical relocations (Lavoie et al., 2015; Salvalaggio et al., 2003; McKenzie, 2015). Many of these negative feelings and issues arise due to the diverse federal, provincial, regional health authorities, hospital and First Nation policies that may apply at different times in a medical relocation.

2.3.1 Federal Responsibility

Health care services for FN peoples living on-reserve or in remote communities is the responsibility of the federal government, however, the level of health service provided by the federal government has a history of inadequacy (Adelson, 2005). Under Section 73 of the Indian Act, the federal government is responsible to provide health services to status Indians; however, this has not been interpreted as a responsibility to provide services but the right to provide services at its discretion (Lavoie et al., 2010). While FNs have requested an autonomous locally accountable system of health-care provision, the government does not admit that health is a treaty right (Adelson, 2005).

To integrate Indigenous health care into the larger national health-care system, the federal government created the Health Transfer Policy (1986). This policy proposed the transfer of health funding and administrative responsibilities to FNs and allowed FNs to determine their own community health needs and the appropriate structures needed to address these needs (Jacklin & Warry, 2012). While the Health Transfer Policy reflects national and international calls for Indigenous participation in and control over health services, the motives of the policy have been highly criticized. The Assembly of First Nations and Union of Ontario Indians have criticized the policy as assimilationist (Jacklin & Warry, 2004). Furthermore, policy examinations of the Health Transfer Policy (1986) have concluded it has become one of the cost containments rather than self-determination (Jacklin & Warry, 2004).

To complicate things further, the federal government of Canada only provides health care to the Inuit population and 'Status Indians', who are registered under the Indian Act, residing on reserves through the First Nations and Inuit Health branch (Lavoie et al., 2015). Non-status

Indians, status Indians who do not live on a reserve fall under the jurisdiction of provincial governments and do not receive health services from the First Nations and Inuit Health Branch.

There are detrimental effects to the ambiguity of jurisdictional responsibilities, as notably seen in the case of Jordan River Anderson, a young boy from Norway House Cree Nation who spent over two years unnecessarily in hospital while the governments of Canada and Manitoba argued over who was responsible for paying for his at-home care (Blackstock, 2012). At the age of 5, Jordan tragically died after waiting for more than two years for the two governments to come to an agreement for the payment of his care (MacDonald, 2007). This case resulted in the government of Canada supporting Jordan's Principle in 2007 (Blackstock, 2012). In November of 2017, an amendment was made to Jordan's Principle, in which the Canadian Human Rights Tribunal issued a ruling that included an expanded definition of Jordan's Principle. This amendment states:

In recognition of Jordan, Jordan's Principle provides that where a government service is available to all other children, but a jurisdictional dispute regarding services to a First Nations child arises between Canada, a province, a territory, or between government departments, the government department of first contact pays for the service and can seek reimbursement from the other government or department after the child has received the service. It is a child-first principle meant to prevent First Nations children from being denied essential public services or experiencing delays in receiving them. (Aboriginal Affairs and Northern Development, 2018)

2.3.2 Provincial Responsibility

Due to the lack of financial contribution from the federal government, the provincial government plays a key role in health delivery for Indigenous peoples. For example, in Ontario,

the Aboriginal Healing and Wellness Strategy is co-managed by representatives from provincial ministries and Indigenous organizations to provide specialized services to off-reserve Indigenous peoples in the form of nurse practitioners, dietitians and researchers (Jacklin & Warry, 2012). It funds both urban and reserve programs and has been essential in funding crisis interventions and traditional healing programs that the federal government has refused to fund.

While the Ontario government provides services to FN individuals living on and off-reserve, other provincial governments are not obligated to extend health services to FN people based on more localized interpretations of policies (Lavoie et al., 2010). The division of responsibility as a result of federal-provincial jurisdictional ambiguities have been occurring since the Constitution Act (1867), which defines health care as a provincial jurisdiction, and Indian affairs as a federal jurisdiction (Lavoie, et al., 2010). This had created a jurisdictional debate over Indian health which remains current to this day (Lavoie, et al., 2010).

The Constitution Act, 1867 (formerly called the British North America Act, 1867, and still known informally as the BNA Act), encompasses the original creation of a federal dominion and defines much of the operation of the Government of Canada. Among other provisions, it. F

2.3.3 Local/Community Responsibility

Through the Health Transfer Policy, 83% of First Nations have opted to participate in the Health Transfer process at different levels of autonomy (Jacklin & Warry, 2012). Five out of the six communities that WAHA services are signatories to the Health Transfer Policy agreement and have voting members on the Board of Directors at WAHA (WAHA, 2019). MCFN is the only community that did not sign the policy agreement, and thus does not have a voting position on the Board of Directors for WAHA but participates with observer status (Moose Cree, 2019).

Many community members from MCFN hold leadership positions within WAHA, making it one of the few FN-governed health authorities in Ontario (WAHA, 2019).

Evaluations of First Nations health programs suggest that enhanced community control over health services has improved the quality and effectiveness of services and allowed for services to be regarded as accessible and culturally appropriate (Jacklin & Warry, 2012). Community-based systems of care that have emerged from this policy can be diverse and unique, yet effective in responding to the needs of particular FNs. However, the community-based approach to health care means that programming and administration is different in each community. Research studies have confirmed that increased Indigenous control over health care leads to improved health care, allowing there to be a relationship between self-determination and community health (Jacklin & Warry, 2012; Bartlett et al., 2007; Adelson, 2005).

While the transfer of health services to First Nations allows for self-determining practices and improved health, there still exist barriers for First Nations who choose to opt into the Transfer Policy. While the Health Transfer Policy allows for the transfer of a range of services, it retains and reproduces the pre-existing dependent relationship on the federal government (Lavoie et al., 2010). For example, First Nations proposals for community health plans are approved by the federal government. The Transfer Policy does not formally recognize the role of traditional healers in transfer agreements and has yet to be addressed by the federal government (Lavoie, 2013; Health Canada, 2006; Assembly of First Nations, 2017).

The participation of all three levels of government creates a highly complicated and uncoordinated system characterized by gaps in service and overlapping coverage. It also results in program duplication and inconsistencies (Lavoie et al., 2010).

2.4 Chapter Summary

Due to the establishment of the reserve land system, Indigenous people were displaced from their traditional lands and territories. The cultural stress this created has negatively impacted the wellbeing of Indigenous communities in Canada and across the world. Additionally, the adoption of the Indian Act of 1867 brought on colonial policies aimed to erase the cultural value, customs and beliefs of Indigenous peoples most notably through the arrival of Christian missionaries and the establishment of residential schools. Due to the intergenerational trauma from hundreds of years of colonial policies and oppression, coupled with the health inequities that Indigenous communities face, Indigenous peoples in Canada have a higher risk of developing multiple chronic conditions (diabetes, arthritis, heart diseases, COPD, dementia, etc.)

Indigenous patients from rural and remote communities must leave their communities to receive specialized health services in larger urban cities for their health conditions. With the lack of cultural, social, and familial supports while away in a larger city, Indigenous patients have expressed having negative experiences with medical relocations. Due to the limited health services in small, remote communities, travelling for medical appointments will remain a reality for Indigenous patients.

The responsibility of delivering health services to FN patients is highly complicated due to the differing interpretations of policies on behalf of the federal and provincial governments.

In the next chapter, the theoretical framework and methodology that guided and informed this project will be discussed.

Chapter 3 : Deciding What is Needed for the Journey (Theoretical Framework)

“Hunters often share stories of their past experiences in particular areas. They help us to think about what we may need on the trip and what to expect... How we see the world is important. The way we think about knowledge is different in different cultures. A strategy of inquiry or a research plan is like a map that helps one arrive at different camps along the way.” (Michell, 2012, p.4)

The theoretical framework that is foundational in this research project is a decolonizing Indigenous research methodology rooted in teachings from Herman Michell’s Cree metaphor that doing community-based research is like going on a canoe trip to hunt for knowledge. The process of preparing for a canoe trip involves careful preparation, planning and collaboration with others (Michell, 2012). Similarly, a research journey involves reflecting on the intent and purpose of the research and how it will benefit both the community and researcher.

3.1 Decolonizing Methodology

Using a decolonizing methodology on which to build this research is imperative, due to the longstanding history of colonization and the continuance of marginalization of Indigenous peoples across the world (Kovach, 2010). A decolonizing methodology allows for conventional, Western research methodologies to be indigenized in order to include Indigenous knowledge and ways of knowing. As stated by Bagele Chilisa (2012),

The indigenizing process challenges researchers to include Indigenous knowledge to inform ways in which concepts and new theoretical frameworks for research studies are defined, new tools of collecting data developed, and the literature base broadened, so that we depend not only on written texts but also on the largely unwritten texts of the formerly colonized and historically oppressed peoples. (p.101)

Centering Indigenous knowledges in the context of decolonization is important because far too often First Nations peoples have been researched on and not researched with (Tuhiwai Smith, 2012).

To ensure a decolonizing Indigenous methodology, this research is framed within the knowledge of the Cree people of the Weeneebayko area. My understanding of the Cree worldview, culture and ways of knowing are informed by people of the Moose Cree territory and through teachings that I have grown up receiving from my Cree grandparents. From this knowledge, I have found that in a Cree worldview, culture and languages come from the land (Michell, 2012). The Cree people of the James Bay lowlands refer to the waterways that make up their traditional territory as Weeneebayko (WAHA, 2018). Long ago, Cree people used the water systems of lakes and rivers to hunt, fish, trade and share with their relatives throughout North America (Michell, 2012). To this day, Cree people from the Weeneebayko region are still living off the land by hunting, gathering, fishing or utilizing the land as a way for mental health therapy and practicing cultural activities and protocols (Lacasse, 2017).

3.2 Community-Based Participatory Research

Traditional protocols of *kistêyihitamowin* (respect), *tâpwewin* (truth) and *kwayaskihtiwi* (honesty) are used in this project to ensure the study is conducted in a good way. From an Indigenous perspective, the idea of doing research “in a good way” is to honour and respect the voices and ideas of Indigenous communities and people in an ethical and positive way (Ball & Janyst, 2008). The research design for this project is guided by eight principles of appropriate community-based participatory research (CBPR) outlined by Jacklin and Kinoshameg (2008). The principles of partnership, empowerment, community control, mutual benefit, wholism, action, communication and respect informed the development of the research project and

continued to be guiding principles throughout the research. These principles were implemented into the study design to ensure that respect, truth and honesty are honoured to the community and people collaborating with the research team on this project.

CBPR is an approach to research that involves collective and reflective inquiry in which researchers and community stakeholders engage as equal partners in all steps of the research process (Tremblay et al., 2018). This design promotes the participation of local community partners throughout the research process that acknowledges inequities, empowers those that are least heard, and engages research methods in Indigenous worldviews (Fraser, 2018).

Historically, research involving Indigenous peoples in Canada has failed to engage Indigenous peoples, communities, and organizations as stakeholders and beneficiaries of evidence from the research (Ninomiya & Pollock, 2017). While CBPR is an approach that questions power relationships embedded in Western knowledge production, this approach does not prevent outside researchers from adopting colonial attitudes towards research (Tuhiwai Smith, 2012). There are many researchers working with Indigenous peoples, communities and organizations who use the term participatory but do not demonstrate true participation and collaboration in order to generate mutually benefitting research. Thus, this project actively draws on best practices and principles co-developed by those who have engaged in respectful methods of CBPR.

3.3 Community Engagement

Community engagement with local health agencies in the Moose Factory and Moosonee area took place early on in the project to identify stakeholders and community partners interested in being involved in the research. I first consulted with workers at the local health centre in Moose Factory where we discussed the proposed project and the possibility of them becoming a

key community partner to guide and support the journey with this research project. During this meeting, the Moose Cree Health Centre committed to providing guidance and were helpful in including community perspective as we began determining the components of the research project. Elements related to the project were carefully reviewed by a representative at the Health Centre who provided helpful feedback relating to research design, interview guides, letters and forms. The Moose Cree Health Center also aided in presenting the project to the Moose Cree Health Committee to seek approval from the FN leadership.

In addition to working with the Moose Cree Health Center, I also consulted and presented my proposed project to the leaders at the WAHA. A project proposal was provided to the health agency, who later expressed interest in the project and in learning of the future results. Through further discussions, WAHA expressed interest to provide funding to support project costs. This funding covered the cost of honoraria and gifts to participants, my personal travel from Sudbury to Moose Factory to complete all stages of the research, as well as a small community meeting to present the results back to community.

3.4 Chapter Summary

This study was guided by the Cree teachings outlined in Herman Michell's (2012) metaphor that doing community-based research is like going on a canoe trip to hunt for knowledge. The use of this framework, along with a decolonizing methodology allowed for conventional, Western research methodologies to be indigenized by including Indigenous knowledge and ways of knowing. Community-based participatory research (CBPR) was used in this study to ensure the project was conducted in a good way. I used the principles of partnership, empowerment, community control, mutual benefit, wholism, action, communication and respect to inform the development of the research project and were guiding principles throughout the

research. To ensure CBPR was employed in this project, community engagement with local health agencies in Moose Factory was integral. Through consultation, I was able to create relationships to create a community partner with the Moose Cree Health Centre, who provided guidance and feedback relating to the project.

Chapter 4 : Gathering Tools (Methods)

“The methods are the actual tools that will help you answer the research questions posed and allow you to arrive at your final destination... Using traditional protocols allows a researcher to conduct a study in a good way... Our Cree ethics of conservation teaches that we only take what we need and nothing more” (Michell, 2012, p.5-6)

As stated by Linda Tuhiwai Smith (2012), “in all community approaches process - that is, methodology and method – is highly important. In many projects the process is far more important than the outcome.” Because of this, the processes in research projects with Indigenous peoples need to be respectful to enable people to heal and to educate (Tuhiwai Smith, 2012).

4.1 Research Design

The intent of this research project was to understand the unique experiences of community members from the Moose Factory and Moosonee area that travel for medical appointments in larger urban cities. Not only did I aim to understand the experiences of patients, I also hoped to understand the challenges and strengths that come with medical travel, envision approaches to improve patient experiences and to provide local leadership with recommendations in improving patient experiences. In order to truly understand the perspective of the patient, qualitative interviews were conducted where patients had the opportunity to share their experiences in which they expressed the positive and negative aspects in having to travel for medical care. Patients were also able to provide feedback on the medical travel process and used their first-hand knowledge to provide their thoughts and recommendations on how their experience could be improved.

4.2 Qualitative Methods

Due to the nature of this project, I chose to conduct semi-structured interviews with 10 community members from the Moose Factory/Moosonee area who shared their personal

experiences when they travelled out of the community for medical appointments. As a community member myself, I felt as though qualitative interviews were best suited for this study due to the nature of the topic that aimed to understand the experiences of patients from their perspective. Qualitative interviews allowed for participants to openly share their experiences in a natural conversational manner and were prompted by general questions relating to the processes and their own experiences in travelling for medical appointments.

4.3 Recommendations from Community Partners

I had a previous relationship with the community partners engaged in this project at the Moose Cree Health Centre through a separate research project on which I had been employed. A few months prior, I had conducted interviews for an unrelated research project that was taking place in the community. When determining the methods for data collection and data analysis for this project, my community partner provided feedback that they were happy with the methods from the previous research project and suggested using similar methods, if possible, in this project. The methods that we decided upon together included in-person, one-on-one interviews with participants to collect data, as well as the use of NVIVO™ data analysis software.

4.4 Ethics & Community Approvals

In November 2019, a letter was presented to the Moose Cree First Nation Health Committee requesting community approval from the FN's leadership for the research project to take place. On January 16th, 2019, approval was provided by the Health Committee during a Special Council Meeting (Appendix "A" on page 101).

An application to the Laurentian University Research Ethics Board (LUREB) was submitted for approval in January 2019. Ethics approval was obtained in March 2019 after one round of revisions to the LUREB.

4.5 Recruitment of Participants

I aimed to recruit 10 participants interested in being interviewed to discuss their experience in having to travel for medical appointments outside of the community. The reason I chose this sample size was to ensure that the individual voices and personal experiences of each participant had the opportunity to be expressed in the writing of this thesis. To recruit participants, I used snowball sampling to recruit participants that fit the outlined criteria. In order to participate in this project, participants were required to be a First Nations individual over the age of 18, who travelled from the Moose Factory/Moosonee region to a larger urban area for health services. Participants also had to have health conditions that required many medical appointments out of the community. This criterion was put in place to ensure that recruited participants had a health condition that they needed specialized medical care for. This criterion also served as a way to ensure that individuals who only attended out of town appointments for optometry or orthodontic treatment were not considered in this project. This was decided together with my community partners, as we discussed the fact that individuals who had serious health concerns that needed treatment would likely offer a different perspective than an individual travelling for a routine eye exam.

Recruitment posters (Appendix “B” on page 102) were posted on public bulletin boards throughout the community, as well as the Moose Cree Health Centre Facebook page. Interested participants reached out to me via email and telephone. From there, we set up an interview time and place that worked best for the participant and me to meet for an interview. At the beginning

of each interview, the participant and I looked through a letter of information (Appendix “C” on pages 103-104) and any questions or concerns were explained or answered. An explanation of the consent form was provided to the participant (Appendix “D” on page 105) which included the topic of the research project and the requirements of the research participants. Participants were made aware that their participation in the research project was voluntary and that they had the option to withdraw from the project at any time. Participants were made aware that signing the form provided consent to be a participant in the project, as well to have their interview audio recorded. Participants had the option to provide verbal consent in the case that written consent was not culturally appropriate. All participants provided written consent during the interview process. During this process, I also let participants know that I would be contacting them in the future to share results with them when I was at that stage. All participants verbally agreed to be contacted in the future.

I was able to recruit 10 participants to be interviewed for the study, one of whom did not fully meet the criteria. This happened to be my first interview and the participant misunderstood that they had to be a patient who was sharing their experiences in travelling for medical care. Instead, she wished to share her father’s story in which she was an escort for his medical appointments out of town. The participant had arrived expecting to be interviewed and felt strongly that she wanted to share her experience. Since the participant had just returned home days earlier from the appointment with her father and the experience was fresh in her memory, I proceeded with the interview despite the participant not fitting the criteria as her experience may have informed the study. This interview was flagged, and I carefully considered whether or not to include it with the rest of the data. In consultation with my committee, I decided that this interview would be included in the study. While the participant could not speak on behalf of her

father's feelings for every question throughout the interview, she was able to explain the situation and process of her father's appointment. She was also able to share some details of how her father expressed how he was feeling during that time, as well as the inferences she made by reading her father's body language and actions.

4.6 Shoving off the Shoreline and Leaving Camp (Methods of Data Collection)

“Finally, we quietly shove off from the shores of our camp. The research process commences. There is rhythm in the paddling, momentum, and energies are high with enthusiasm. Eagles soar in the sky and remind us that we must look far into the past and far into the future. We meet and listen to travellers who have been placed in our path, paying attention to the nuances. We learn to read between the lines. There are hidden teachings in Cree words. We share in reciprocity.” (Michell, 2012, p.5)

Ten interviews were conducted in person in Moose Factory, Ontario between June 20th and August 4th, 2019. Using a semi-structured interview guide (Appendix “E” on page 106) participants shared their unique experiences in having to travel for medical care. Questions covered the patient's experience prior to an appointment, travelling to an appointment, during an appointment, and reflecting on the experience as a whole. All interviews were audio-recorded and lasted between 10-40 minutes in length. The length of each interview was dependent on the participant, and how much the participant wished to elaborate on questions. Each participant was compensated \$50 for their time in participating in the research project.

The audio-recording of each of the interviews were then transcribed verbatim and saved on the password-protected Laurentian University Google Drive. All identifying information was removed from the transcripts to ensure anonymity. After personally transcribing all of the interview, I reviewed each transcript multiple times while listening to the audio-recording to ensure no errors were found in the transcripts.

4.7 Description of Participants

To better understand the results to follow, it is important to understand the participants who were interviewed. As previously mentioned, 10 face-to-face interviews took place with community members from the Moose Factory/Moosonee area. All 10 participants involved in this study were females of varying ages (see Table 1 on page 50).

Table 1

Age Distribution of Participants

Age Range (years)	Number of Participants
20-29	2
30-39	1
40-49	5
50-59	2

4.8 Summary of Health Conditions

As mentioned, a specific criterion for this project was that participants must have a health condition that required multiple appointments out of the community. Participants were asked about their health condition during the interview to confirm this criterion. Information about the health conditions of the participants were not used for any other purpose. The majority of the participants had multiple chronic conditions, including diabetes, high blood pressure, arthritis, kidney disease, hypertension and chronic pain. A few participants also had mental health issues, which increased the number of health appointments they had out of the community.

4.9 Patterns of Stories and Interviews (Data Analysis)

“In the data analysis phase, we look at the overall pattern of messages. What are voices telling us? We see the saturation of data, a signal it is time to bring the journey to a close.” (Michell, 2012, p.6)

Similar to data collection, the community partners involved with this project advised early on that data analysis should follow the same process as previous research projects that have taken place in the community. Thus, I used NVIVO™ analyze the data. This allowed for results to be reported back to the participants in a timely manner and allowed for greater organization of the data.

Once the audio-recordings were transcribed, I used the six phases of thematic analysis described by Braun and Clarke (2006) in Table 2 (page 52). In order to ground this process of thematic analysis in Indigenous methodologies, I included participant check-ins throughout the data analysis process. Initially, I intended to have two participant check-ins; however, after the first round of participant check-ins, nearly every participant was pleased with the preliminary results. Due to time and financial constraints, and to ensure my participants were not being overburdened by setting up another meeting time, one round of participant check-ins was held as participants felt this was sufficient for them. The details of this process are described in section 4.8.2 on page 53.

Table 2

Thematic Analysis Process

Phase	Description of the Process
1. Familiarizing yourself with the data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Reviewing themes	Checking in the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic ‘map’ of the analysis
5. <i>Checking in</i>	<i>Checking in with academic committee and participants involved in the project. Participants have the opportunity to provide feedback on early results.</i>
6. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tell; generating clear definitions and names for each theme
7. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Adapted from Braun & Clarke, 2006, p. 36

4.9.1 Coding

During the coding process, I made sure that I was carefully and thoughtfully coding each interview in the same way using the NVIVO™ software to ensure accuracy across all interviews. While coding each interview, I coded sentences to a node related exactly to that sentence. NVIVO™ (2020) describes a node as a “collection of references about a specific theme”. Once all interviews were coded, I reviewed each interview a second time to ensure each sentence was

properly coded to the nodes. I then grouped all of the similar nodes together, creating adult nodes and child nodes. A careful review of all nodes was then completed to ensure any similar or like nodes were grouped together. Within this step, themes were determined from the data, in which I began defining and naming each theme. Pseudonyms were also assigned for each participant rather than ID numbers. This allowed for confidentiality for each participant, and also veered away from a numbering system that could be compared to the numbering system used in residential schools.

4.9.2 Participant Check-Ins

To ensure community-based participatory research was being completed, I also included participant check-ins in the data analysis process. I met with 8 of my participants from January to March 2020 in person in Moose Factory. I reached out to each participant letting them know I had early results to share with them and requested to meet with them in person. During the meeting with each participant, I shared an interactive presentation that used Michell's (2012) canoe trip framework to describe the entire research process and preliminary results. Presenting the results using this framework allowed participants to better comprehend the components of the research as they could relate and understand the terms and metaphors used within this Cree framework.

The results I shared with participants were well accepted and many participants expressed they were happy and excited with the results. Many participants expressed how there were things they forgot to mention during their interview but were glad to see that other participants mentioned them and that these things were highlighted in the results I shared. No participant had any issues with the results, and instead shared additional stories that I noted and wrote down after the check-in. At the end of the meeting, I gave a small handcrafted birch bark canoe to each

participant as a gift, thanking them for their time and contribution to the research project. In a Cree worldview, *mekiwin* (gift giving) is a common protocol to thank storytellers for sharing their time and knowledge, and to recognize that their knowledge has value.

Two participants were unable to complete in-person member check-ins. One participant had moved away for school and was no longer in the community to have an in-person meeting. Instead, I emailed her a copy of the presentation I shared with each participant and gave her a phone call. Together we went through the presentation and I explained to her the results the same way I had for every other participant. The second participant also was not in the community during the time of the participant check-ins as she was giving birth outside of the community. Because of her situation, and then becoming a new mother, I did not feel it was appropriate to request a meeting during a busy and stressful time. I will reach out to this participant once it feels appropriate, and I will give her the option to see if she is interested in meeting and seeing the results.

4.10 Evaluating Qualitative Research

Lincoln and Guba (1985) developed criteria to evaluate qualitative studies and ensure rigor, also described as trustworthiness. The criteria they developed provide me with a tool to evaluate the credibility, transferability, dependability and trustworthiness of my qualitative study (Lincoln and Guba, 1985). While each of these strategies have been used for decades to critically evaluate qualitative research, some argue that not all of these criteria can be used to evaluate all qualitative research studies (Morse, 2015). Morse (2015) provides a detailed outline of what strategies should be used with data collected through semi-structured interviews to ensure validity is obtained through the project. The strategy used in this study to ensure that the information gathered reflected as closely as possible what the participants provided was

prolonged engagement. Member checking was also utilized in this study to ensure the participation and involvement of participants in the analysis process, and to ensure principles of community based participatory research were employed.

4.10.1 Prolonged Engagement for Thick, Rich Data

In exploring strategies to determine validity in qualitative studies utilizing interviews, Morse (2015) explains that prolonged engagement is necessary for producing thick, rich data. In having prolonged engagement and spending time getting to know the interviewer, participants are able to establish a more trusting relationship with the interview (Morse, 2015). With increased trust, the data will result in better, richer data, allowing more to be revealed and therefore, the data will be more valid (Morse, 2015). Morse (2015) also explains that studies that specifically use interviews, in the process of retelling one's experience, the participant internally focuses on their experiences and provides rich data when they have an opportunity to gain trust with their interviewer.

In being a member from the same community as the participants, I was able to create better connections with the participants involved in this study. I knew each of the participants on a personal level in coming from a small, tight knit community. This allowed participants to have greater trust and connections to me as an interviewer, and I believe participants were able to open up and explain their experiences with ease, as their stories were being shared with someone who deeply understood the context in which they were happening. In addition, when discussing the research project at the beginning of each interview, I was able to share my connection to the research and shared my own personal stories with participants. I believe these reasons allowed participants to be vulnerable in the telling of their stories as well.

4.10.2 Member Checking

Since the data obtained from this study was detailed, rich, and descriptive, member checking occurred throughout the data analysis process for reliability checks and verification. Member checking during the analysis phase took place during this project as many participants expressed interest in hearing early results rather than receiving and reviewing their transcript. Member checking during the analysis process was also important to myself as a researcher, as I wanted to ensure that participants were made aware of results and had the opportunity to provide comment and provide feedback. Since the results will be shared back with the FN and local health authority, it was important that the participants heard of results first, as I did not want them to learn of results through a community report or through word of mouth within the small community. This form of member checking is consistent with the principles of communication and respect outlined by Jacklin and Kinoshameg (2008) to do community-based participatory research in a good way.

4.11 Chapter Summary

This research project aimed to understand the unique experiences of community members from the Moose Factory and Moosonee area that travel for medical appointments in larger urban cities. I also aimed to understand the challenges and strengths that come with medical travel, envision approaches to improve patient experiences and to provide local leadership with recommendations in improving patient experiences.

With the help of the community partners engaged in this project, we were able to determine a plan for the methods to be used in this study. The methods that we decided upon together included in-person, one-on-one interviews with participants to collect data, as well as the use of NVIVO™ data analysis software.

Snowball sampling was used to recruit participants that fit the outlined the inclusion criteria. The individuals eligible for inclusion in this project were First Nations individuals over the age of 18, who had travelled from the Moose Factory/Moosonee region to a larger urban area for health service, and who had health conditions that required many medical appointments out of the community.

Ten interviews were conducted in person in Moose Factory, Ontario. Using a semi-structured interview guide, participants shared their unique experiences in having to travel for medical care. Questions covered the patient's experience prior to an appointment, travelling to an appointment, during an appointment, and reflecting on the experience as a whole. Interviews were then transcribed verbatim. The transcripts were then imported into NVIVO™, which was used to analyze the data. This allowed for results to be reported back to the participants in a timely manner and allowed for greater organization of the data.

An adapted version of Braun and Clarke's (2006) six phases of thematic analysis was used to inform the thematic analysis process. To ensure that the analysis was grounded in Indigenous methodologies, I included a participant check-in during the data analysis process. The next chapter will cover the main themes that emerged from the interviews with patients who travelled for medical appointments in an urban city.

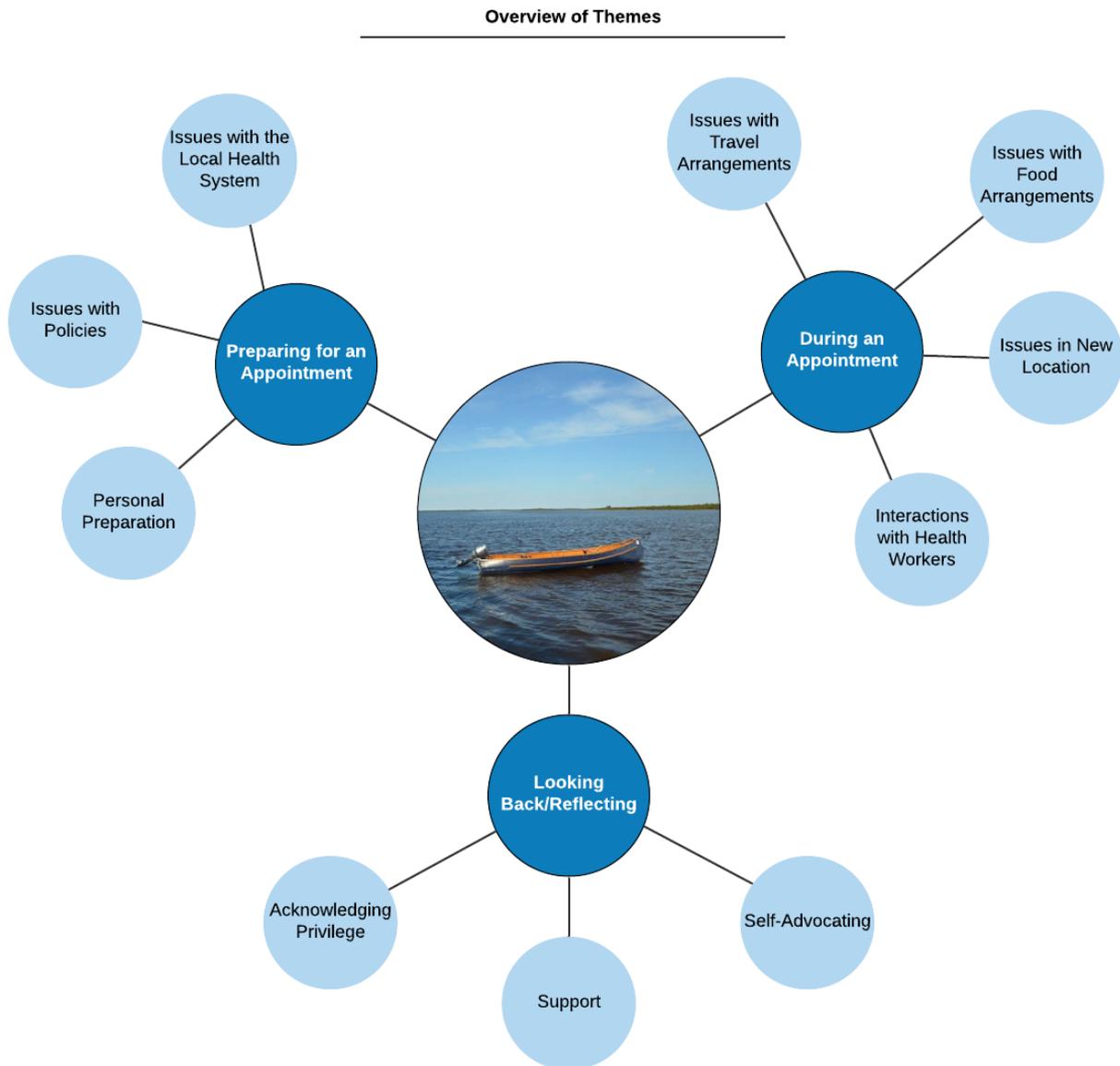
Chapter 5 : Feeding on Northern Foods of Wisdom for Survival (Results)

“We shove off from the shores and head for our final destination. The paddles are once again in unison... We are grounded and focused on the incredible diversity of perspectives. Like the boreal forest trees, we honor and respect the different shapes, sizes, colours, and "rooted-ness... The voices of research participants speak through you. What you write reflects the landscape of where those voices originate.” (Michell, 2012, p.6)

In this chapter, findings from data analysis are presented and shared in the way that they occur throughout the process of attending an out of town appointment. Similar to the stages of a canoe trip, there are also stages to a patient’s experience of travelling for a medical appointment. The main themes that emerged from this research will be classified under the three stages of leaving home for an appointment out of town. These stages include preparing for an appointment, travelling and attending an appointment, and returning home and reflecting after an appointment (see Figure 4 on page 59)

It is important to note that the findings presented in this chapter are specific to the participants of this study and should not be generalized to be true for other communities or groups of people. While these are only the experiences of the people who participated in this study, they still offer an insight into the perspective of patients who travel for medical care.

Figure 4
Overview of Themes



5.1 Participant Experiences Preparing for an Appointment

In order to attend an appointment out of town, preparation must occur for an appointment to be made. In sharing their experiences, participants described numerous issues with the local health system, policies and referral process in order to get their out of zone appointment scheduled. They also shared the personal preparation it takes for them to be able to attend their appointments out of town.

5.1.1 Issues with Local Health System

Throughout numerous interviews, participants expressed their frustrations towards the health system in Moose Factory and Moosonee. Because of the constant turnover of physicians in the community, participants felt as though their file sometimes falls through the cracks of the health system. Rose, for example, shared a story about how it took multiple visits to the hospital to get a referral to see a specialist for her health problems:

Because the thing with family medicine, the clinic is that I feel like they're so overworked... I've been going there for months and months and months. And no one was looking at it, like my file just kept passed on because the [doctors] were just rotating. There's so much rotation of doctors. So, I was like, you know, when I would finally call to see what's going on, they'd be like oh, I don't know what happened. You know, like, they would straight up [say], "I don't know what happened [to your file]" (Rose).

Participants also expressed their frustrations with the complaint system at WAHA, explaining that their complaints, requests and recommendations were not being heard, describing that their complaints fell all on deaf ears. They discussed their frustration in how their concerns are not followed up by the local health authority.

In discussing the needs for their health condition, many participants described the lack of health services in their community. Many discussed how the services of a massage therapist, physical therapist, and a foot care nurse played a positive role in the treatment of their health problems and explained how these professionals no longer provided services in the Moose Factory and Moosonee region. Other participants discussed the lack of technology in the community and that results of tests weren't provided in a timely manner, as compared to larger urban hospitals.

5.1.2 Issues with Policies

Throughout the interviews, a common sentiment felt among numerous participants was frustration relating to the difficulty in navigating through Health Canada policies regarding medical travel and out of town appointments. Some of the policies resulted in a negative effect on the participants' health. Marjorie described her health issues in which her and her doctors tried finding a medication that worked for her. Through trial and error, they tried a number of medications. She described her experience in having to stay on medications that didn't work for months until she could be prescribed a new one. In addition to having to wait for months to find a prescription that worked, she was diagnosed with new health conditions due to having to stay on medications for a certain length of time.

It was maybe like a two-year process before we could find something that worked. And, the problem with that is I had to stay on it for about, at least 6 months or longer in order for them to actually change it. So, NIHB would approve different meds. I find that really dumb so I would be like in pain, say, for like six to eight months. I had to be on it, these medications, for a certain amount of time to say that they don't work... But in the process, they ended up prescribing me Prednisone, which I could only take a small

dosage, because of the severe side effects that has for long term usage. So, me being on that, I ended up being type 2 diabetic, because that affects your sugars.

Participants also discussed the issues with zones and policies that state that patients must travel to partnered hospitals of Kingston or Timmins primarily to have their medical travel covered by NIHB. Nicole explained that an eye condition she has that requires biannual trips to a specialist. When she was first diagnosed with the eye condition by her regular optometrist, he referred her to a well-respected specialist in Toronto. For the year that she had her eye condition, NIHB covered her travel to attend four of her appointments in Toronto. The following year she was told the policy changed and she had to see a new specialist in Kingston, rather than Toronto. Because of the severity of her eye condition, Nicole didn't feel comfortable going to a new specialist in Kingston and starting her treatment over. Instead, she decided to stay with her original specialist in Toronto and pay for her travel out of pocket.

What keratoconus is, is that my cornea... it's going into a cone shape. And as it goes into a cone shape, gravity affects it, and it's kind of like a pop tent losing air, he described it. That the structural integrity would lose, and then it would collapse. So, it would become opaque and I would become blind. If they would not treat it... I decided to stay with [the eye specialist in Toronto] because I just felt that, you know, he's, he's the one who diagnosed me and I felt that I was frustrated because NIHB just said no, you need to come to Kingston. And I said, "but I just had my procedure and you're like, you're telling me I need to start from, yeah I need to get reassessed". And I felt like I needed to step, take three steps back if I went that way. But, you know, it has affected me financially because I pay for my own way to Toronto.

Another participant discussed the troubles with policies relating to travelling with a child. Alice had to attend an appointment for her health problems and was unable to find childcare for her grandson that she was the sole caretaker for. In an attempt to keep her long-awaited appointment time, she decided to bring her grandson and to pay for his travel. When she asked if she could be provided a hotel room with two double beds instead of one, she was met with resistance and was upset with the lack of understanding:

I can't leave my grandson alone. So anyways, um, so I said, "can you guys not book me a room with two beds?" like, you know? I said, "I see parents taking their kids all the time". I said, "just because I'm not a parent, like, I have to pay for that?" I said, "I'm a grandparent, I'm raising my grandson", I said, "I've had him since he was 1". He's 14 now, and he's 6 foot. Do you expect me to sleep with him? Like he's 6 foot, 200 pounds. And um, then, uh, they said, uh, "No, well you're not, you're not paid to take your grandchildren out". And I said, "I know", I said "I'm not paid to take them out", I said, "I'm not asking you to pay his fare, or his food or anything. Just give me a double bed is all I'm asking, like, two separate beds, that's all I'm asking". And she said, "we have a policy", and I said, "well I'd like to see your policy, because anywhere that I read on WAHA's policies" I said, 'I've never seen anything about, uh, taking children". (Alice)

Alice also discussed her frustrations that policies are made by people who have never experienced travelling from remote Northern communities to urban cities for a medical appointment:

And, you know, I, I honestly wish that those people that make these decisions in Ottawa would actually try one of these trips to actually first-hand do these trips (Alice).

5.1.3 Personal Preparation for Out of Town Appointments

In order for patients to attend their appointments out of town, participants discussed the level of personal preparation that they needed to do. For many of the participants, childcare was something they needed to coordinate with their partners and/or family members to attend their appointments out of town. This preparation was especially difficult for single mothers or those caring for their grandchildren. Alice explains the complexity of her situation to attend her appointments: “It is hard, because I'm raising my grandson and sometimes, I have to make accommodations for him because my husband works 12-hour shifts, 4 days on, 4 days off. So, it's hard, and there's only two of us that live with him” (Alice).

Participants also explained how they used additional health services in the city when they travel for an appointment out of town. For example, participants discussed that they planned appointments to get a massage or acupuncture done while they were in an urban city for an appointment. These are additional services that participants paid out of pocket but were happy to do so as a part of their self-care routine.

5.2 Travelling and During an Appointment

Participants shared their experiences while they were away for their appointment. The themes in this section are the most prevalent across all of the data and were discussed in length by many of the participants. These include issues with travel arrangements, transportation services, and food arrangements. Participants also shared their experience with their healthcare provider during their appointment.

5.2.1 Issues with Travel Arrangements

A sentiment that was common among the interviews was that many participants did not feel prepared for their travel or their appointment out of town prior to leaving Moose Factory or Moosonee. Participants shared experiences where they were informed of their appointment very last minute, sometimes receiving a call that their travel was booked for the very same day. This caused participants to panic and rush to get prepared for their travel and appointment. One participant described the process she experiences when she travels out of town:

When you leave here you basically don't know nothing, which you should have received your envelope in Moose Factory, beforehand explaining where you should be going. Instead of when you get to Kingston, all of a sudden, they hand you an envelope and then they say, "here you go". Drop you off at the hotel, with a little map showing like the hospitals and restaurant areas where you can go. (Marie)

Another participant discussed whether or not she feels prepared for her travel or appointment:

No, they just give you the package. You're on your way. Nothing is really said about your trip because they, they expect you, you should know... And we always get our tickets the last possible minute that we're leaving. (Alice)

When discussing the travel for their appointment, participants shared stories of previous experiences and the process they now take on themselves in order to ensure their travel and accommodations are booked:

I actually bother Moosonee [NIHB travel office] on my own, just to make sure I'm on there, just because of a mishap one time where I was not informed, I was moved to the

next day on a charter... And we had gone over the day that I thought I was scheduled, that I told I was scheduled, whereas nobody contacted me to tell me I was moved to the next day... Ever since then, I make sure I'm on the day I'm supposed to be on. *laughs*. Because that was quite annoying. I was quite annoyed with that. (Marjorie)

Other participants shared their experiences when miscommunications occurred, causing issues with their travel or accommodations. Ann shared an experience she had where there was an issue with her travel arrangements for her appointment. The Polar Bear Express train had recently changed their train schedule, running two less days a week. This change in the train schedule was not accounted for and it caused Ann to miss her appointment as the train did not operate on the day she needed to travel. Her appointment ended up getting rescheduled but when she arrived in Timmins, her hotel had not been booked by the WAHA NIHB department. She ended up having to book and pay for her hotel room on her own and later got reimbursed when she returned home.

I feel like, just the people who arrange travel and all that don't really contact the people who are, where we're going. Let's say my therapist, they always have trouble communicating with each other. Because I had an incident where I always had to pay my own hotel...They forgot the whole train schedule [had changed] and they had to reschedule me the next day for another appointment. (Ann)

Alice also shared her thoughts on the miscommunication between the organizations that coordinate patient's appointments and travel. She explained the difficulty of getting answers from the two NIHB offices in Kingston and Moosonee:

One of the downsides of that too was um, it, there's always miscommunication here. Like, I find nobody knows what the right hand and the left hand is doing. If I call and ask questions, they don't seem to know. Um, they say "Oh, we gotta call you back", "oh we gotta do this". And I'm thinking, don't you have all my information there on paper?

(Alice)

Participants that were specifically in Timmins for their appointment shared that they ran into a number of issues. Participants shared their thoughts on the hostel and disorganization in Timmins:

There are things, because, umm, especially the hostel in Timmins, they have to communicate more. You know, the umm, like meal tickets, simple stuff like that, meal tickets, even hotel arrangements. Umm, what time your appointment is. Because a lot of the times, the paper is not correct (Sara).

5.2.2 Issues with Transportation Services

Transportation services are said to be provided to patients arriving in Kingston or Timmins, as well as to and from patient appointments in these towns (NIHB Working Group, 2013). Many participants shared stories citing issues with these transportation services. Marjorie shares a story of a time she arrived in Timmins and was expecting to be picked up from the bus station by transportation services and brought to her room for the night:

I find though, with my experience from going to Timmins... You're getting off the bus late at night, and sometimes the driver's not even there. You have to call them. Whereas another time, I had gone to treatment a year or two ago... And same thing, right. I had to call them to come meet me. Like, where am I staying?... I mean, they should have this information about who's expected and all of that, right? So, when I came back through

again, nobody was there to meet me. And I had to, actually because I didn't have a cell phone at that time, I had to actually call I think one of my sisters to tell them to call the hospital to call Timmins, to send somebody to pick me up. Like, they didn't even have that information about arrivals, who's coming where, who's coming in what day. So that's with Timmins... I think they need to be more informed and more aware of time arrivals for people coming in from different areas. Because a lot of people do utilize other treatment centres in other locations, and they don't have cell phones and stuff like that. (Marjorie).

Another participant discussed the challenges with transportation she faced while she attended her medical appointments in Kingston:

Basically, trying to get from one point to another. You have no idea where you're going. And if you don't have like the cash to take a cab from here to there then you're going to have to get on the bus to figure out where your stop is, and where you're gonna get off at the hospitals... Or if you're in a different place to go, like me, I take a cab to go to my uh, pain clinic. They give me taxi vouchers, or they have the local services van pick you up and drive you to and from your appointments. When they're available... (Marie)

Alice shared her experience when she attended an appointment in Timmins and was waiting to be picked up from her hotel and brought to the hospital for her appointment:

And um, then the other thing I noticed, too, like uh, when, when I did go by bus, um, I'm at my hotel waiting for the shuttle to come pick me up. And apparently, they only have one [shuttle]. Which is a real, which is not even close to being good. Um, for, for patients. And you know what uh, when I asked the lady, I said "How come you came so late? You know, I'm supposed to be at that appointment an hour before my appointment!"

And she goes "well, our first thing is we have to go to the airport for the client's that are flying in". And I said "Well, I don't mind that", I said, but I said, "I do need to get to my appointment, too". I said, "I'm important, just like them!" *laughs*. And they said, "well we only have one vehicle." I said "Well that's not good, either... You know, because, like I said, your rides are not, um, um, they're not dependable. Even when we get into the bus station late at night. There's only one cab sitting there, and it's already filled by the time we're getting off, and, but anyways, that's part of the thing. So, um, yeah. So that's the mode of transportation. (Alice)

5.2.3 Issues with Food Arrangements

An interesting theme that emerged in the data was the many issues with food arrangements for patients while they are away for their appointment. Many participants explained that they are provided meal tickets with their travel package. Meal tickets can be used at a select few restaurants and cafeterias in both Kingston and Timmins. One participant described that the current system set up to feed patients on the day of their return travel home is ineffective. Patients leave Timmins via bus on the morning of their travel at 6:30 am. Often times, a sit-down breakfast before a 6:30am bus ride is not realistic for all patients. When patients arrive in Cochrane after an hour and a half bus ride, there isn't enough time to get a meal at the sit-down restaurant in Cochrane, either. This leaves patients having to wait until they get on the train to eat breakfast. As a diabetic, Alice did not think this system is effective and can be harmful to those who need to eat to regulate their sugars: "And nobody packs you little baggies, like you know, to say "oh okay here's your breakfast". I'm diabetic for God's sake! *laughs*. You know, I gotta eat. And sometimes, not all the time, but sometimes I get shaky when I don't eat."

Alice shared another story of a time she and her grandson were travelling from Kingston to Timmins by bus. The bus departed Kingston in the evening, and they were not able to eat supper at the bus station restaurant before they left. She describes her 16-hour bus ride:

But, and then, coming back *laughs*, they take us, our, um, they didn't give us supper, we were leaving at 4[pm], they take us to the bus station, didn't give us no baggy again, like I said. Get to the bus station they said "oh the restaurant will be open there, and you'll be fine" you know. So, we get there, fricken restaurant is closed. *Laughs*. And I said, "we hadn't even eaten supper yet", and we're getting ready to go on a 16-hour bus ride, no food. So, we got on the bus, hungry, no food, no drinks... And then we got in to, I'm not sure if it was Toronto or somewhere anyways, they stop at this place at 6:00 in the morning. I don't know which town, city, it was, but they get there at 6 o'clock in the morning, they let us off to go eat breakfast and I go "thank goodness, I'm fricken starving". By then, we're starving... And um, I, I think that's one of the biggest issues, myself. Is um, not feeding the patients properly. (Alice)

Other participants expressed their concerns over the system in which patients are provided meals while away for their appointment. Specifically, participants shared their concern about elders with diabetes eating proper meals and at times in which they need to eat to regulate their sugars.

Other participants expressed that they felt they were treated poorly by restaurant staff that accepted meal tickets. Participants described that as soon as they let restaurant staff know their meal was being covered by a meal ticket from NIHB, the service provided to them was poor.

Rose shared her experiences with restaurant staff:

Like, for example, you go to Timmins and you go to Mike's and you pull out that, that voucher. They're like *makes degusted facial expression*, like you know what I mean.

Like, the attitude completely shifts. And like, every single time, like anywhere you go, as soon as you have anything that does anything to do with NIHB it's like, “oh, are you kidding me?” (Rose).

5.2.4 Experience with Doctors or Healthcare Workers During Appointment

During the interview, participants were asked about their experience with their doctor or healthcare workers during their appointment. The majority of participants shared that they had positive experiences with their doctor/healthcare provider. Many of them explained that due to the number of appointments with the same doctor(s), they were able to build a relationship. In having a relationship with their patient, participants described that their doctor was understanding of the NIHB health system and was helpful in providing any additional documentation or letters that patients needed.

A few participants had experiences with their doctor/healthcare provider that were not positive. The participants who did not have positive experiences with their doctor instead shared stories in which they felt they were experiencing racism from their healthcare providers. Ann shared that while she was away and admitted into the mental health unit at the Timmins hospital, a nurse made a racist comment towards her: “But I just, I don't know, I just wanted to get out of there as quick as possible, but they didn't let me. They just told me I was just there for a free ride and free medicine and all that, free food (Ann)”.

Charlotte also shared that she felt like her father was not receiving proper care from her father’s nurse who cared for him for a couple days while he was admitted to the hospital. She noticed this nurse was not tending to her father as closely as his other nurses were and was upset when she noticed that her father had not been showered or had his bed made in a number of days. Charlotte made a complaint to the nurse in charge of the department in which her father was in

about the lack of attention given to her father. She describes her father's demeanor while in the hospital:

And when he got moved up to the floor, there was some days that he didn't want me to leave. And then when they discharged him to the hotel the night before we came home, he told me, "when you leave it's like they don't check on me, or they'll say I'll be back", like he was almost crying (Charlotte).

5.3 Looking Back/Reflecting

As participants were able to look back on their experiences during appointments, they were able to reflect and share their thoughts during the interview. Themes that emerged from the data while participants reflected were the acknowledgement of their own privilege, whether or not they felt supported during their trip away for an appointment and realizing the self-advocating they do for themselves. Participants also shared the positive aspects of travelling for medical appointments they enjoyed and provided some of their own recommendations on how to improve patient experiences while travelling to a new city for health services.

5.3.1 Acknowledging privilege

An interesting theme that emerged in the data was that many of the participants acknowledged their own privilege while reflecting on their travels to attend appointments. Many participants shared that although they may have been able to navigate difficult or frustrating situations, they were more concerned about other people having to go through the same situations. Some participants shared that they were fortunate to have either a disposable income, a strong voice to self-advocate, or the knowledge to navigate Western systems in order to overcome the obstacles that occurred during their appointment. They also brought up that they

were concerned for elders who had language barriers and those who do not have extra funds to pay for things in an emergency situation or if there were issues with travel arrangements. They also noted that patients from communities further along the James Bay coast may not have cell phones to call for rides if transportation was not available.

5.3.2 Support

During the interview, patients were asked if they felt supported during their trips out of town for an appointment. In the analysis of participants' answers, it's clear that each participant described support in different contexts. Some participants expressed that they did not feel supported for their appointment due to a number of issues arising in the travel process. Other participants expressed that they had no issues in feeling supported because they knew how to navigate systems in a new city.

A few participants expressed that they were fortunate to have family in the city they were travelling to, and their family was able to provide support to them while they were in the same city for their medical appointment. These participants were able to rely on their family for rides to get to their appointments or to do leisurely activities after their appointment.

Another participant shared that she doesn't feel supported by the health system in Moose Factory and Moosonee. This is due to the fact that she has not received a follow up or response from the health authority in which she shares her complaints and recommendations on issues that arise while patients travel for medical appointments.

5.3.3 Self-Advocating

Throughout each interview, there was a common theme among many participants in that they served as strong advocates for themselves throughout the process to attend an out of town

appointment. Some participants discussed that in order for things to move along in a timely manner with the referral and booking process, they would have to call the hospital and NIHB offices asking for updates on appointment times and travel itineraries in order for everything to be arranged properly and for the participant to feel prepared. Marjorie shared the process she uses in order for her appointments to go smoothly:

But [when] I have to well go out for my appointment, I gotta call Kingston to confirm, then I gotta call Moosonee to call and confirm, and I usually do that a month before. I know my schedule, of my scheduled appointment, just to remind them I'm coming. And I usually do this before they even send me the letter... And then say a week before I'm supposed to go, I call to see, I call Moosonee to see if they actually have my travel arrangements. And then "No." They haven't received it yet. And then I'll call 2-3 days before I actually leave to make sure that I'm on the charter and in the process I also have to call Kingston too, when I first call there to let them know I'm bringing an escort and I have to give them their name. And so, they gotta do their, their letter, send it down to Moosonee. So, I call to make sure I'm on there and my escorts on there... I would just get a letter, but like, you said I'm proactive. My doctor gives me my appointment card, I keep that on me, so I know to always follow up a month before I do this, on my own, and usually before the letter from Kingston comes in. And I actually bother Moosonee on my own, just to make sure I'm on there, just because of a mishap one time where I was not informed I was moved to the next day on a charter.

5.4 Positive Aspects of Travelling for Medical Appointments

Participants were asked during interviews to share any positive aspects of travelling for medical appointments that they enjoyed. Across each interview almost every participant shared

there was a positive aspect they enjoyed while visiting a new city. When reflecting on their health, some participants expressed that they enjoyed the advanced scans and tools that were used during their out of town appointments. Participants shared that they were able to find out results of scans much quicker out of town than in the community. They also expressed that there is a wider range of services available in the city that participants access than what is offered in the community.

Some participants enjoyed being able to shop and buy groceries, clothes, household supplies, etc. at an affordable price than what is offered in their Northern community. Others discussed that they enjoyed certain leisure activities, like eating out at a restaurant. Those who travelled to places where they had family that lived or was in the same town enjoyed being able to visit and spend time with family that they did not see on a regular basis. While some described that sometimes appointments feel like a break, Rose shared the reality of being a sick patient and needing medical care: “It's nice to get a little vacation. But I mean sometimes when you're sick you just don't want to have a vacation; you know what I mean. You just wanna, just get the help that you need (Rose).”

5.5 Suggestions for Improvement from Participants

During each interview, participants were asked if they had any thoughts or ideas on things that could be improved in order to improve a patient’s experience when they have to travel for medical appointments. While all of the suggestions and thoughts may not be completely possible to achieve, it is important that the thoughts and concerns of the participants are shared.

The majority of suggestions by participants included giving patients more freedom on the types of transportation to travel for their appointment. Participants had their own preferences on

which mode of transportation they preferred to travel to their appointment and wished to have the option to choose.

Other participants suggested improving the patient support system in Timmins, specifically relating to transportation services and at the hostel in which patients frequently stayed. Participants described that having better communication and organization in these areas would allow for better experiences for patients travelling to Timmins for an appointment.

Another participant suggested a way to improve the issue with meal tickets and feeding patients in the morning would be to provide a bagged breakfast to ensure patients had something to eat before a travel day until they could get to a place where they could eat a full meal.

Some participants suggested bringing in different services and specialists up to the community. One participant shared that there are a number of community members that would utilize services if they came to the community every couple of months. Another participant shared that many people from the community see the same specialists for certain health problems. These participants suggested making arrangements to bring these specialty services to the community and coordinate with community members to see them while they are in the community.

5.6 Chapter Summary

In this chapter, nearly every participant had an issue at one time or another with medical transportation during their travels to out of town appointments. Participants also discussed their frustrations while they prepared for an appointment, namely addressing the issues with the local health system, issues with policies, and the personal preparation they must undertake in order to attend an appointment out of town. While away for their appointment, participants discussed in detail issues with the food arrangements and issues specifically taking place while patients travel

to Timmins. Participants also discussed their interactions with health workers during their appointment. In looking back and reflecting on their experience, participants shared whether or not they felt supported during the trip and were also able to recognize the self-advocating they do for themselves, as well as acknowledging their privilege through the whole experience. In closing this chapter, the recommendations that participants suggested during their interviews are shared as well.

Chapter 6 : Bringing it All Together (Discussion)

“The editing process will take the research team through winding rivers, small streams, deep reflection in ponds, and down tight corridors that refine and polish what has been written. We look at our emerging and collective knowledge. Did we cover everything that needs to be told? Has the initial research question been answered? What have we learned? We see things other people do not see.” (Michell, 2012, p.7)

This research study aimed to understand the unique experiences of community members from the Moose Factory and Moosonee area that travel for medical appointments in larger urban cities. It also aimed to understand the challenges and strengths that patients face and intended to provide a space for participants to envision ways on how this process could be improved.

The interviews revealed a number of themes that were identified between 10 different participants’ experiences. Major themes emerged for each different stage of a patient’s journey to attending an appointment in a larger urban city. The following sections will take an in-depth look at the major themes and explore their relationship to current literature.

6.1 Preparing for an Appointment

While discussing the preparation for an out of town appointment, participants shared their frustrations with the local health system in Moose Factory and Moosonee, specifically, the lack of continuity with their care. Participants who visited the hospital in Moose Factory to get answers for their health issues explained how long it took them to hear back from a doctor at the hospital. Patients describe having to call repeatedly the hospital and ask for updates on their file. This is likely due to the difficulty that FN communities experience in recruiting and retaining long term physicians and thus have to rely on short-term locum physician positions (Minore, et al., 2005). Dignan (1998) describes that nursing and physician shortages in FN communities’ results in a crisis where patients receive sporadic and inconsistent care, an increase in client

backlogs and patients who are ‘lost in shuffle’ of referrals. Patients with serious diagnoses lack follow-up education (Dignan, 1998). These issues prove to be significant barriers in providing the patient with appropriate information related to their health conditions (Dignan, 1998). While physician turnover will likely remain a reality in remote FNs, the local health authority has begun to take steps to recruit and retain more permanent physicians as a shift in the health authority’s executive team took place in June 2019. WAHA announced the hiring Lynne Innes, the first Indigenous woman to be president and CEO of a health authority. In addition, local community member, Dr. Elaine Innes was hired as chief of staff and the community has seen an increase in permanent physician hires (Bonello, 2020).

Participants also shared their frustration with WAHA’s lack of follow up relating to the complaints and requests regarding medical travel. Participant’s expressed that even if they took the time to file a complaint relating to their experience, they felt as though their words “fell on deaf ears”, as the same issues continued to happen to them. Recent studies point out that patient complaints can provide great potential value in understanding and improving systems of care and therefore should be carefully considered (Montini, et al., 2008). Addressing and following up with complaints may also allow patients to feel supported and validated in sharing their negative experiences. Systems of classifying patient complaints have been discussed and may serve as a helpful tool to organize and respond to patient complaints in a timely manner (Montini, et al., 2008).

Participants also mentioned their concern over the lack of health resources in the community. Some of the resources lacking in the community included medical technology and scans, as well as a lack of health services that would be beneficial to a patient’s treatment plan. These treatments included physical therapists, foot care specialists, massage therapists, among

others. This reality is likely due to the lack of adequate health funding provided by the federal government to local health structures, as well as the difficulty to recruit and retain specialized health workers in remote Northern communities (Martens et al., 2002; Minore, et al., 2005).

While it may not be realistic to have these specialized health services in the community on a full-time basis, participants have suggested that WAHA and MCFN work together to gather community interest for different health treatments and coordinate bringing these specialists into the community every so often. This allows patients to stay in the community and receive health services for which they would otherwise have to travel out of the community.

The data also revealed that many participants had issues with the process and policies in place that affect how they receive health care. Policies that determine the location of where they receive their out of zone care, the mode of travel they must use during medical travel, the type of medications that are covered and the lack of accommodating special instances were discussed in detail by the participants of this study. A number of the participants expressed their frustration towards the WAHA NIHB office when sharing their stories related to policies. It is completely understandable for participants to feel this way, but it is important to note that many of these policies are not created by the WAHA NIHB department and are decided upon by the federal government (Lavoie, *et al.*, 2010). The policies have been founded on colonial beliefs that emphasizes paternalism, dependency, victim blaming, and medicalization (Waldram, Herring, & Young, 2006). Additionally, the existence of settler colonialism in Canada has created an uneven distribution of benefits and harms to settler and Indigenous populations (Sylvestre, et al., 2019). The uneven distribution of benefits (e.g., good health), privileges (e.g., access to health care), violence's (e.g., non-consensual medical experimentation), and harms (e.g., systemic intergenerational trauma) has resulted in health disparities that continue to exist between

Indigenous and settler peoples (Sylvestre, et al., 2019). The existence of settler colonialism is an organizing feature of the settler state's governance of Indigenous communities and is illustrated through settler ignorance and anti-Indigenous racism (De Leeuw, et al., 2020). In order to address these inequities, it is imperative that learners and practicing clinicians are grounded in the knowledge of ongoing colonial harms and are engaged in critical self-reflection on one's own biases and training in order to conform anti-Indigenous racism in health care (Cook, et al., 2019).

Numerous studies show that tactical and discriminatory practices and policies continue to marginalize many FN people in mainstream health care systems (Browne, 2005, 2007; Smith, Varcoe, & Edwards, 2005). In this study, participants described their own processes to prepare for an appointment out of the community in relation to the existing policies and practices. Many participants discussed the need to coordinate childcare and the difficulties that come with this, as well as having to inform their employers of their absence. Lawford and Giles (2012) have critically examined policies affecting pregnant women in FN communities and have called on the government and stakeholders to recognize the colonial influence in these federal policies. They argue that addressing the issues with these policies is imperative to ensure First Nations achieve optimal health, as defined by First Nations themselves (Lawford & Giles, 2012). The descriptions of how participants prepare for appointments clearly show how much personal work and preparation goes into attending an appointment out of town. Not only does this require effort and careful planning by the participant, but it also requires effort and support from participants' family and friends, whether they are aiding in childcare, elder care, or house sitting while the patient is away for an appointment.

6.2 Travelling and During an Appointment

While describing their experiences in travelling and attending an appointment, nearly every participant shared detailed recounts of their experiences where issues with travel arrangements occurred. Participants discussed not feeling prepared for their travel or their appointment and received their travel itinerary at the very last minute. Many shared stories where miscommunication between NIHB offices, hotels and hostels, and transportation services resulted in patients having to pay out of pocket for taxis, hotels and meals. It is evident from the data analysis that issues with travel arrangements is by far the theme most discussed by participants, who shared their negative feelings towards the disorganization of medical travel arrangements. While we are unaware of the logistics of how this department at WAHA runs, it is evident from patient's stories that there is room for improvement through increased communication and organization in all locations. Providing patients with travel itineraries, hotel information, meal tickets and taxi vouchers with enough time before their travel date to prepare would allow for participants to feel more prepared for their appointment and travel. Giving patients their travel packages sooner would likely result in less issues arising than if these important items were provided in last minute nature.

Similarly, participants shared their concerns over the transportation services that are said to be provided to patients travelling to Kingston or Timmins. Many participants described the reality when utilizing these services, describing that there are only a few shuttles available, giving priority to those who are arriving from the airports, and are often too busy to provide reliable services to all patients who require them. For patients who may have been on long waitlists for an appointment with specialists or for surgeries, it is essential that these patients arrive and arrive on time to these long-waiting appointments. Not only may these appointments

provide patients with answers and important information related to their health situations, but it may also provide patient's with great relief depending on their health condition. Because of this, it is essential that transportation services for patients are available and dependable. In the case there is no capacity to acquire shuttles, hiring of additional staff and an organized transportation itinerary for each day, it is imperative that patients are provided with taxi information and vouchers to pay for their transportation to and from their appointments.

Another theme discussed by participants were issues with food services in cities in which patients were travelling to. Patients shared their experiences specifically relating to travelling from Timmins to Cochrane early in the morning and not having time to sit down at restaurants for a full meal. This is especially worrisome to those who have health conditions, like diabetes, and need to regulate their sugars by eating meals. Additionally, a participant shared her experience where she boarded a 16-hour bus ride without eating dinner. Dinner was not provided to the participant and the restaurant at the bus station was closed prior to their departure. This participant described how travelling through the night resulted in all bus stops being closed and she was unable to purchase anything out of her pocket. Instead, she had to wait until the bus arrived at the destination for her to eat breakfast, the next morning, after 16 hours on the bus. This was an isolated incident and was only experienced by one participant involved in this study, but it truly highlights how food arrangements and ensuring patients have access to food is integral for patient wellbeing. Although it isn't entirely possible for WAHA to know the operating hours of restaurants and bus stops throughout a patient's travel journey, it is possible to better inform patients of the possibilities of restaurant closures and to encourage patients to plan ahead and be prepared. Another suggestion from this participant was to have arrangements for patients travelling in the morning or on long bus rides to be given a small boxed meal and/or

snacks for patients to have in case of emergencies. This requires additional planning and logistics to be considered but may be useful to ensuring patients are receiving proper nutrition, especially those who are elderly or have medical conditions.

When discussing interactions with their doctor or healthcare provider during appointments, many participants described having a positive experience. Many participants expressed that this was due to the fact that they had visited their doctor a number of times and were able to create a trusting relationship with them. Patient-doctor relationships are critically important, and it has been determined that patients' trust in doctors is positively associated with adherence to treatment, continuity of care, willingness to recommend the physician to others, and self-reported health (Petrocchi, *et al.*, 2019). Birkhaèuer *et al.* (2017) state that patients who claim higher levels of trust with their health care professional report more beneficial health behaviours, less symptoms, and a higher quality of life. While it is great that some participants had a close and trusting relationship with the doctors whom they may see more frequently, there were other participants who did not have a positive experience with their healthcare provider. Some participants shared how they experienced racism during their stays at a hospital, specifically by the nurses providing care. One participant specifically described a nurse making racist and stereotypical comments, stating that the participant was only seeking medical help so she could have a free place to stay, free medicine, and free food. These damaging stereotypes of FN peoples perpetuate racism at all levels of Canadian society. In healthcare settings, FN people experience a disproportionate burden of interpersonal and systematic racism compared to non-FN people (McNally & Martin, 2017). Thus, it is important for healthcare workers to engage in cultural safety training to ensure they are not perpetuating negative stereotypes onto Indigenous patients. Cultural safety requires healthcare professionals to reflect upon their own biases and

stereotypical assumptions and the way power and racism operates and impacts patients (McNally & Martin, 2017). It is imperative that health leaders in the community and health authority continue to advocate for community members and encourage healthcare providers in major referral centres to receive cultural safety training.

6.3 Looking Back & Reflecting

Throughout the interviews, participants had an opportunity to reflect on their experiences and share their thoughts. One of the main reflections participants shared was a realization of their privilege despite the challenges they went through. Many participants discussed how fortunate they were to have had a disposable income, a cell phone, and the ability to navigate issues in larger cities. Many of them reflected on their concerns for others, specifically, elderly people facing these same issues, some even reflecting on those from further up the James Bay coast who may face language barriers in a new town. Others reflected on how there were some community members who didn't have jobs or an income to pay for hotels, food or taxis in an emergency or when there were issues with their travel arrangements. In reflecting on my own during the data analysis process, it was interesting to hear so many participants share their concern for others, just minutes after sharing very challenging and upsetting experiences of their own. Not only does this reflection made by so many participants show the compassion and care they have for their elders, other community members, and even other communities, but it also shows that the experiences and stories shared within this study were those of people who still consider themselves to hold privilege. It's important to reflect on this as there are likely many more patient experiences who may be similar to those in this study, but who may have to overcome additional barriers.

Patients also had the opportunity to reflect on whether or not they felt supported while they were away for their appointment. Some participants expressed that they did feel supported, while others shared strong feelings that they did not. It is clear that support is something that is subjective to each person and that different people feel support in different ways and from different people. Some patients shared that they were able to feel supported when they travelled to locations where they had family members that also lived in the same city. Family members were able to provide support by giving rides to patients to their appointments, as well as leisurely activities. Other participants expressed that they didn't feel as though they needed additional support from other people or the health system, as they were self-sufficient people who could navigate systems and new cities on their own.

A number of participants shared that they did not feel supported due to the lack of preparedness they felt in not having their travel arrangements completed properly or in a timely manner. This sentiment demonstrates that patients require sufficient notice of their travel plans for an appointment. As discussed previously, there is much preparation that a patient has to do prior to leaving town and not having sufficient time to make these plans can be stressful and difficult for them. To ensure patient stress is lowered, it is important for WAHA to respond to the challenges patients are facing related to their medical travel plans by enacting changes and steps to inform patients with enough notice prior to travel day.

Through reflecting, some participants realized how much they served as advocates for themselves throughout the process of attending an out of zone appointment. Participants discussed how they used their voice and stood up for themselves when there were issues throughout the journey to attend an appointment. Hearing many of the stories that these participants shared highlighted the resiliency and strength they showed to overcome the

challenges they were facing. Some participants talked about how their health and their experience was important and were able to express this by voicing their concerns to their doctors or WAHA if issues occurred. It is important that patients continue to stand up for themselves and advocate for their health, but it is imperative that the health and experiences of those who may not feel comfortable vocalizing their thoughts are advocated for as well.

Another participant reflected on the self-advocacy process she completes while preparing to attend an appointment out of town. This participant shared her in-depth process to ensure that her medical travel is booked properly, describing that she begins calling NIHB offices up to a month before her scheduled appointment. This reflection serves as an indicator that patients have developed habits to ensure their medical travel goes smoothly. While this method may work well for this participant, it should not be a reality for community members to constantly check in and remind health workers of their appointment and travel arrangements in order for everything to go smoothly. Improvements in service delivery for medical travel are required for patients to feel prepared and supported for their appointments.

6.4 Recommendations for Improvements

In the context of health, the Truth and Reconciliation Commission concluded that advancing the health opportunities for Indigenous peoples requires us to identify and remove barriers to health systems that Indigenous peoples in Canada face in their day-to-day lives. This study provided an in-depth examination of the experiences of patient's as they leave the community for an appointment in a larger urban city. In listening to patient experiences, we were able to identify where patient's face challenges throughout the process of attending out of zone appointments.

It is important for those in health leadership positions in the community to be aware of these findings and work to improve patient experiences. The experiences of the ten women who participated in this study are important as they highlight the challenges that FN women go through while they are in larger urban cities for medical appointments. These unique experiences of these women are of great importance as:

Aboriginal women lag behind men and well behind Canadian women as a whole on many social and economic [and health] indicators, but statistics do not reveal why. Women themselves provide a deeper understanding of the barriers that have been placed in their path, barriers that must be recognized, acknowledged and removed before real progress can be made. We believe that by going through the process of acknowledging the harm caused by these barriers, individuals, families, communities, nations and governments will be able to work together to eliminate them (Royal Commission on Aboriginal Peoples, 1996).

Thus, the following recommendations are provided to local leadership at Moose Cree First Nation, the Moose Cree Health Centre, and the Weeneebayko Area Health Authority:

Recommendation 1: Improved internal communication systems within WAHA to better inform patients. Some areas of improvement include:

- Increasing communication systems by following up with patients with issues or complaints with the medical relocation process.
- Providing patients with more notice of medical travel plans prior to their travel date to allow for patient's to adequately prepare and make personal plans while they are away.

- Improve communication and organization of patients' medical travel, including reliable transportation services in new locations, hostel and hotel arrangements, and ensuring patients have access to food arrangements that support healthy living.

Recommendation 2: Continued advocacy by health leadership in the community for increased funding for the following areas:

- Local infrastructure, including updated scans and tests to ensure patients can stay in the community as much as possible and to ensure results are provided in timely matter.
- Traditional healing programs to treat and serve patients in ways that align with a Cree worldview.
- Bringing alternative care practitioners into the community for patients to access for their health conditions, such as chiropractic, podiatry, nutrition, naturopathy, occupational therapy, among others.
- Increased funding in education to promote local community members being trained in alternative health therapies

Recommendation 3: A deep and honest reflection into the current health system in which anti-Indigenous racism exists. Current areas that need to be addressed include:

- The health disparities that occur in communities within the WAHA region.
- The current racist mistreatment of patients by health practitioners, hotel workers, transportation workers, and restaurant workers.
- The current meal ticket system that has harmful impacts on patients experiencing racism.

Recommendation 4: Continued advocacy by health leadership for cultural safety training grounded in anti-racist theory for healthcare providers in the main referral centres away from their home communities. Additionally, cultural safety training is needed for workers and staff

interacting with patients in main referral centers. This includes the staff at the restaurants, hotels, hostels and transportation services that provide services or interact with patients.

Recommendation 5: A deep examination into the current partnership with KGH and TDH and the effectiveness of these referral centers to patients. Additionally, an examination into potential centers in Northern Ontario that could possibly better treat patients closer to home, such as North Bay or Sudbury.

Chapter 7 : Final Reflections & Conclusion

The objectives of this project were to understand the experiences of patients when they travel for medical appointments in urban cities, understand the challenges and strengths that come with medical travel, envision approaches to improve patient experiences and to provide local leadership with recommendations in improving patient experiences.

The stories that the participants shared in this study allowed for greater understanding of the process and a patient's experience while they prepare for an appointment, travel to attend their appointment, and return home. In sharing their stories, it was clear to see where patients experience challenging times throughout the process of attending appointments out of town. Participants also provided helpful reflections on the positive aspects in the process and provided thoughtful suggestions on how they believed the medical travel process could be improved.

The results of this study were translated from patient experiences in travelling for medical appointments into recommendations that could be used by the local FN leadership to advocate for improvements to the healthcare system that affects their community members. These recommendations also are helpful to the local health authority that currently services patients in the Moose Factory and Moosonee region. In addition to being translated into recommendations, the results also provide a greater insight to local health workers and leadership into the realities that community members face while they are away for medical appointments in larger urban cities.

7.1 Navigating Through Rough Terrain (Limitations of the Study & Further Research)

“Factor in flexibility for unexpected twists and turns of the research journey. Embrace the ambivalence and flux as the weather can change, the river waters may become tumultuous, and the terrain may be rugged, making for slow travel. It is during these times that great learning takes place. Things always happen for a reason. Lessons learned are documented along with challenges encountered by using the research design.” (Michell, 2012, p.5)

Due to the diversity between Indigenous groups of people, the structure of health services and levels of displacement for health services are different between Indigenous communities. Thus, the findings in this project will not reflect all Indigenous populations in Canada, nor do they reflect the realities across all FNs.

While the participants in this study provided deeply personal insight into the patient experience relating to medical travel as women, there is a lack of male perspective in this study. Indigenous men and women have different experiences and realities navigating through institutional systems (Royal Commission on Aboriginal Peoples, 1996) and having the perspective of male patients could be informative to future studies.

In addition, this study only accounted for the experience of patient’s who first-hand attend appointments for their own medical conditions. While recruiting participants for this study, I was overwhelmed with people wanting to share their experience but did not fully fit the criteria. Many community members who may not have been a patient, but who had been an escort for their children, elderly parents or grandparents had great interest in the project and wished to be involved. Future studies could explore this topic, as the perspectives of others who also travel for medical appointments would be different, yet interesting. It would be especially informative to understand the experiences of the escorts who support the elderly generation, as this population would likely have a more difficult time navigating larger cities and urban centers than the sample that was interviewed in this study.

7.2 Celebration of the Research Journey (Strengths of the Study)

“We look across the vast lake and to our final destination. The dark clouds begin to recede and there is a heavy smell of earth and soil in the air. We breathe it in deeply, Spirit touching where we need healing. We paddle away in fervour. Our families on the shoreline are waving and patiently waiting.” (Michell, 2012, p. 7)

This research project was framed in a way that reflected my own core values and teachings as a Cree person, but also reflected those of many of the participants. This framework allowed me to better comprehend and reflect on the research process, but also allowed me to explain the research process to the participants involved in this study in a way that they also understood. Additionally, the use of the decolonizing Indigenous methodology in this research project allowed for this study to be based from an Indigenous and Cree worldview. Because the research was grounded on these elements, the research highlighted and amplified the voices of the FN patients involved in this study.

One of my personal goals throughout this study was to be involved in something that was meaningful yet beneficial to my community and other community members. The stories shared with me throughout this process truly emphasized the resiliency and strength of the participants who shared them. Although the stories that were being shared were difficult and heavy at times, each participant found ways to navigate through challenging situations and were eager to offer suggestions and solutions to improve what they experienced. It is my hope that the lessons I have learned through this journey will allow me to continue to work in the field of collaborative projects that will hopefully improve patient experiences in the future. It is also my hope that local leadership can respond to the recommendations that were translated from each participant’s experience. I look forward to supporting the necessary work that needs to be done to ensure patient experiences are improved in the future. Meegwetch!

Chapter 8 : References

- Aboriginal Affairs and Northern Development Canada. (2011). *A history of Indian and Northern Affairs Canada*. Retrieved August 27th, 2018, from: <https://www.aadnc-aandc.gc.ca/eng/1314977281262/1314977321448>
- Aboriginal Affairs and Northern Development (2018). Definition of Jordan's Principle from the Canadian Human Rights Tribunal. Retrieved June 2nd, 2020, from: <https://www.sac-isc.gc.ca/eng/1583700168284/1583700212289>
- Adams, D. W. (1995). *Education for extinction: American Indians and the boarding school experience*. Lawrence: University Press of Kansas.
- Adelson, N. (2005). The Embodiment of Inequity: Health Disparities in Aboriginal Canada. *Canadian Journal of Public Health*, 96, 45-61. Retrieved from: <http://journal.cpha.ca/index.php/cjph/article/view/1490/1679>
- Allan, B., & Smylie, J. (2015). *First Peoples, second class treatment: The role of racism in the health and wellbeing of Indigenous peoples in Canada*. Toronto: the Wellesley Institute, 2015.
- Assembly of First Nations. (2017). *The First Nations Health Transformation Agenda*. Retrieved from: https://www.afn.ca/uploads/files/fnhta_final.pdf
- Ball, J. & Janyst, P. (2008). Enacting Research Ethics in Partnerships with Indigenous Communities in Canada: "Do it in a Good Way". *Journal of Empirical Research on Human Research Ethics: An International Journal*, 3(2), 33-51. Retrieved from: <https://journals.sagepub.com/doi/abs/10.1525/jer.2008.3.2.33>

- Bartlett, C., Marshall, M. & Marshall, A. (2012). Two-Eyed Seeing and other lessons learned within a co-learning journey of bringing together indigenous mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences*, 2, 331-340. Retrieved from: <https://link.springer.com/article/10.1007/s13412-012-0086-8>
- Bartlett, J.G., Iwasaki, Y., Gottlieb, B., Hall, D. & Mannell, R. (2007). Framework for Aboriginal-guided decolonizing research involving Métis and First Nations persons with diabetes. *Social Science & Medicine*, 65, 2371-2382. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/17689163>
- Birkhaèuer, J., Gaab, J., Kossowsky, J., Hasler, S., Krummenacher, P., Werner, C. & Gerger, H. (2017). Trust in the health care professional and health outcome: a meta-analysis. *PLoS One*, 12 (2). Retrieved from: <https://doi.org/10.1371/journal.pone.0170988>.
- Blackstock, C. (2012). Jordan's Principle: Canada's broken promise to First Nation Children?. *Paediatric Children's Health*, 17(7), 368-370. Retrieved from: <https://cwrp.ca/publications/jordans-principle-canadas-broken-promise-first-nations-children>
- Bombay, A., Matheson, K. & Anisman, H. (2014). The intergenerational effects of Indian Residential Schools: Implications for the concept of historical trauma. *Transcultural Psychiatry*, 51(3), 320-338.
- Bonello, J. (2020, January 28). Friend, colleagues bid farewell to renowned Sioux Lookout physician. *The Sioux Lookout Bulletin*. <http://www.siouxbulletin.com/friends-colleagues-bid-farewell-to-renowned-sioux-lookout-physician>

- Braun, V., Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. Retrieved from:
http://eprints.uwe.ac.uk/11735/2/thematic_analysis_revised...
- Browne, A. J. (2005). Discourses influencing nurses' perceptions of First Nations patients. *Canadian Journal of Nursing Research*, 37(4), 62-87. Retrieved from:
<https://cjr.archive.mcgill.ca/article/view/1971>
- Browne, A. J. (2007). Clinical encounters between nurses and First Nations women in a Western Canadian hospital. *Social Science & Medicine*, 64(10), 2165-2176. Retrieved from:
<https://www.ncbi.nlm.nih.gov/pubmed/17395350>
- Bruce, S.G., Riediger, N.D. & Lix, L.M. (2014). Chronic disease and chronic disease risk factors among First Nations, Inuit and Métis populations of northern Canada. *Chronic Diseases and Injuries in Canada*, 34(4), 210-217. Retrieved from:
<https://www.ncbi.nlm.nih.gov/pubmed/25408180>
- Canadian Institute for Health Information. (2010). *Have health card, will travel: Out-of-province/-territory patients*. Retrieved from:
<https://secure.cihi.ca/estore/productSeries.htm?pc=PCC521>
- CBC News. (2017, October 17). Indigenous man's death en route to hospital prompts call for inquiry. *CBC News*. Retrieved from: <https://www.cbc.ca/news/canada/manitoba/niki-ashton-abraham-donkey-1.4867331>
- Chamberlain, M., & Barclay, K. (2000). Psychosocial costs of transferring indigenous women from their community for birth. *Midwifery*, 16(2), 116-22. Retrieved from:
<https://www.ncbi.nlm.nih.gov/pubmed/11151547>
- Chilisa, B. (2012). *Indigenous Research Methodologies*. Los Angeles: Sage.

- Cook, C., MacKinnon, M., Anderson, M. & Whetter, I. (2019). Structures last longer than intentions: creation of Ongomiizwin – Indigenous Institute of Health and Healing at the University of Manitoba. *International Journal of Circumpolar Health*, 78, 1-4. Retrieved from: https://journals-scholarsportal-info.librweb.laurentian.ca/pdf/22423982/v78i0002/nfp_slltichatuom.xml
- Couchie, C. & Sanderson, S. (2007). A report on best practices for returning birth to rural and remote Aboriginal communities. *Journal of Obstetrics and Gynaecology Canada*, 29(3), 250-254. Retrieved from: [https://www.jogc.com/article/S1701-2163\(16\)32399-4/abstract](https://www.jogc.com/article/S1701-2163(16)32399-4/abstract)
- De Leeuw, S., Maurice, S., Holyk, T., Greenwood, M. & Adam, W. (2012). With Reserves: Colonial Geographies and First Nations Health. *Annals of the Association of American Geographers*, 102(5), 904-911. Retrieved from: <https://www-jstor-org.librweb.laurentian.ca/stable/pdf/23275564.pdf>
- Dignan, T. A. (1998). A report to Shibogama First Nations Council from community physician. Sioux Lookout, ON: Shibogama First Nations.
- Duran, E., & Duran, B. (1995). Native American postcolonial psychology. Albany: State University of New York Press.
- Fraser, S.L. (2018). Why stories to tell? A trilogy of methods used for knowledge exchange in a community-based participatory research project. *Action Research*, 16(2), 207-222.
- HayGroup. (2016). Weeneebayko Area Health Authority (WAHA) Operational Assessment Project Report. <https://www.waha.ca/wp-content/uploads/2017/06/WAHA-Operational-Assessment-Project-Report-Final-SUBMITTED.pdf>
- Health Canada. (2006). The Evaluation of the First Nation and Inuit Health Transfer Policy. http://publications.gc.ca/collections/collection_2016/sc-hc/H14-191-2006-eng.pdf

- Jacklin, K., Kinoshameg, P. (2008). Developing a Participatory Aboriginal Health Research Project: “Only if it’s Going to Mean Something”. *Journal of Empirical Research on Human Research Ethics: An International Journal*, 3(2), 53-67.
- Jacklin, K., Pace, J.E. & Warry, W. (2015). Informal Dementia Caregiving Among Indigenous Communities in Ontario, Canada. *Care Management Journals*, 16(2), 106-120.
- Jacklin, K. & Warry, W. (2004). The Indian Health Transfer Policy in Canada: Towards self-determination or cost containment? In: Singer, M. & Castro, A., eds., *Unhealthy Health Policy: A Critical Anthropological Examination*. Walnut Creek, CA: Altamira Press, 215–233.
- Jacklin, K. & Warry, W. (2012). Decolonizing First Nations Health. In: Kulig, J.C. & Williams, A.M., eds, *Health in Rural Canada*. Vancouver, BC: UBC Press, 373-389.
- Kornelson, J., Kotaska, A., Waterfall, P., Willie, L. & Wilson, D. (2011). Alienation and Resilience: The Dynamics of Birth Outside Their Community for Rural First Nations Women. *Journal of Aboriginal Health*. Retrieved from: <http://med-fom-crhr.sites.olt.ubc.ca/files/2012/02/alienationandresilience.pdf>
- Kovach, M. (2010). Conversational method in Indigenous research. *First Peoples Child & Family Review*, 5(1), 40-48. Retrieved from: http://www.jordansprinciple.org/sites/default/files/onlinejournal/vol5num1/Kovach_pp40.pdf
- Lacasse, N. (2017). *Indigenous Culture as a Strategy to Deter Mushkegowuk Youth from Criminal Behaviour in Moose Cree First Nation*. (Master’s Thesis). Retrieved from: <https://zone.biblio.laurentian.ca/bitstream/10219/2794/1/Masters%20Final%20N.Lacasse.pdf>

- Lavoie, J.G. (2013). Policy silences: why Canada needs a National First Nations, Inuit and Métis health policy. *International Journal of Circumpolar Health*, 73(1), 1-7. Retrieved from: <https://www.tandfonline.com/doi/pdf/10.3402/ijch.v72i0.22690?needAccess=true>
- Lavoie, J., Forget, E.L. & Browne, A.J. (2010). Caught at the Crossroad: First Nations, Health Care, and the Legacy of the Indian Act 1. *Pimatisiwin*, 8(1), 83-100. Retrieved from: https://www.researchgate.net/publication/265197453_Caught_at_the_Crossroad_First_Nations_Health_Care_and_the_Legacy_of_the_Indian_Act_1
- Lavoie, J.G., Forget, E.I., Prakash, T., Dahl, M., Martens, P. & O'Neil, J.D. (2010). Have investments in on-reserve health services and initiatives promoting community control improved First Nations' health in Manitoba? *Social Science & Medicine*, 71, 717-724. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/20554364>
- Lavoie, J.G., Kaufert, J., Browne, A.J., Mah, S., O'Neil, J.D., Sinclair, S. & BlueSky, K. (2015). Negotiating barriers, navigating the maze: First Nation peoples' experience of medical relocation. *Canadian Public Administration*, 58(2), 295-314. Retrieved from: https://www.researchgate.net/publication/265197453_Caught_at_the_Crossroad_First_Nations_Health_Care_and_the_Legacy_of_the_Indian_Act_1
- Lawford, K. & Giles, A.R. (2012). An analysis of the evacuation policy for pregnant First Nations women in Canada. *AlterNative*, 8(3), 329-342. Retrieved from: <https://doi.org/10.1177/117718011200800308>
- Lincoln, Y. S., & Guba, E. (1985). *Naturalist inquiry*. Newbury Park, CA: Sage Publications.
- MacDonald N, Attaran A. (2007). Jordan's Principle, governments' paralysis. *Canadian Medical Association Journal*, 177, 321-23. Retrieved from: <https://pubmed.ncbi.nlm.nih.gov/17698813/>

- Marrone, S. (2007). Understanding barriers to health care: a review of disparities in health care services among indigenous populations. *International Journal of Circumpolar Health*, 66(3), 188-198. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/17655060>
- Martens, P., Bond, R., Jebamani, L., Burchill, C., Roos, N., Derksen, S., et al. (2002). *The health and health care use of registered First Nations people living in Manitoba: A population-based study Winnipeg*. Manitoba Centre for Health Policy. Retrieved from: http://mchp-appserv.cpe.umanitoba.ca/reference/rfn_report.pdf
- McKenzie, C. (2015). Medevac and Beyond: The Impact of Medical Travel on Nunavut Residents. *Journal of Aboriginal Health*, 80-88. Retrieved from: https://www.researchgate.net/publication/310845290_Medevac_and_Beyond_The_Impact_of_Medical_Travel_on_Nunavut_Residents
- McNally, M. & Martin, D. (2017). First Nations, Inuit and Métis health: Considerations for Canadian health leaders in the wake of the Truth and Reconciliation Commission of Canada report. *Healthcare Management Forum*, 30(2), 117-122. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/28929885>
- Michell, H. (2012). The Canoe Trip: A Northern Cree Metaphor for Conducting Research. *In Education*, 18(1), 2-8. Retrieved from: <https://ineducation.ca/ineducation/article/view/4>
- Minore, B., Boone, M., Katt, M., Kinch, P., Birch, S. & Mushquash, C. (2005). The Effects of Nursing Turnover on Continuity of Care in Isolated First Nation Communities. *CJNR*, 37(1), 86-100. Retrieved from: <https://cjr.archive.mcgill.ca/article/view/1928>
- Montini, T., Noble, A.A. & Stelfox, H.T. (2008). Content analysis of patient complaints. *International Journal for Quality in Health Care*, 20(6), 412-420. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/18801751>

- Morse, J.M. (2015). Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. *Qualitative Health Research*, 25(9), 1212-1222. Retrieved from: <https://journals-sagepub-com.librweb.laurentian.ca/doi/pdf/10.1177/1049732315588501>
- Non-Insured Health Benefits Working Group. (2013). *Weeneebayko Area Non-Insured Health Benefits Working Group*. Weeneebayko Area Health Authority.
- Northern Ontario School of Medicine (NOSM). (2020). Vision, Mission and Values. *Northern Ontario School of Medicine*. Retrieved from: <https://www.nosm.ca/about/about-nosm/vision-mission-and-values/>
- Ninomiya, M.E. and Pollock, N.J. (2017). Reconciling community-based Indigenous research and academic practices: Knowing principles is not always enough. *Social Science & Medicine*, 172, 28-36.
- NVIVO™. (2020). *About Nodes*. NVIVO™ for Mac Help. Retrieved from: http://help-nv11mac.qsrinternational.com/desktop/concepts/about_nodes.htm
- Petrocchi, S., Iannello, P., Lecciso, F., Levante, A., Antonietti, A. & Schulz, P.J. (2019). Interpersonal trust in doctor-patient relation: Evidence from dyadic analysis and association with quality of dyadic communication. *Social Science & Medicine*, 235, 112391. Retrieved from: <https://ideas.repec.org/a/eee/socmed/v235y2019ic9.html>
- Reading, J. (2009). *The Crisis of Chronic Disease among Aboriginal Peoples: A Challenge for Public Health, Population Health and Social Policy*. Retrieved from: <http://cahr.uvic.ca/nearbc/documents/2009/CAHR-B2-Chronic-Disease.pdf>
- Richmond, C.A.M. & Ross, N.A. (2009). The determinants of First Nation and Inuit health: A critical population health approach. *Health & Place*, 15, 403-411. Retrieved from: <https://www.ncbi.nlm.nih.gov/pubmed/18760954>

- Royal Commission on Aboriginal Peoples (1996). *The Report of the Royal Commission on Aboriginal Peoples* (Vols. 1–5). Ottawa, Canada: Minister of Supply and Services.
- Salvalaggio, G., Kelly, L. & Minore, B. (2003). Perspectives on health: experiences of First Nations dialysis patients relocated from remote communities for treatment. *Canadian Journal of Rural Medicine*, 8(1), 19-24. Retrieved from:
<https://search.proquest.com/openview/d19d92188ddf527f88a09415198699c2/1?pq-origsite=gscholar&cbl=45825>
- Smith, D., Varcoe, C., & Edwards, N. (2005). Turning around the intergenerational impact of residential schools on Aboriginal people: implications for health policy and practice. *Canadian Journal of Nursing Research*, 37(4), 38-60. Retrieved from:
<https://www.ncbi.nlm.nih.gov/pubmed/16541818>
- Sylvestre, P., Castleden, H., Denis, J., Martin, D., & Bombay, A. (2019). The tools at their fingertips: How settler colonial geographies shape medical educators strategies for grappling with Anti-Indigenous racism. *Social Science & Medicine*, 237, 1-9. Retrieved from: https://journals-scholarsportal-info.librweb.laurentian.ca/pdf/02779536/v237/complete/nfp_ttatfhsfgwar.xml
- Truth and Reconciliation Commission of Canada. Truth and Reconciliation of Canada: Calls to Action. (2015). Retrieved from: http://trc.ca/assets/pdf/Calls_to_Action_English2.pdf
- Tuhiwai Smith, L. (2012). *Decolonizing methodologies: research and Indigenous peoples*. London: Otago University Press.
- Waldram, J. B., Herring, A. D., & Young, T. K. (2006). *Aboriginal health in Canada: Historical, cultural, and epidemiological perspectives*. Toronto, Ontario: University of Toronto Press.

Weeneebayko Area Health Authority. (2018). *Site Histories*. Retrieved from:

<https://www.waha.ca/site-histories/>

Weeneebayko Area Health Authority. (2019). *Board of Directors*. Retrieved from:

<https://www.waha.ca/board-directors/>

Weeneebayko Area Non-Insured Health Benefits Working Group. (2013).

Wilson, K. (2003). Therapeutic landscapes and First Nations people: An exploration of culture, health, and place. *Health & Place*, 9, 83-93. Retrieved from:

<https://www.sciencedirect.com/science/article/pii/S1353829202000163>

Zacharias, J., Komenda, P., Olsen, J., Bourne, A., Franklin, D. & Berntein, K. (2011). Home

Hemodialysis in the Remote Canadian North: Treatment in Manitoba Fly-In

Communities. *Seminars in Dialysis*, 24(6), 653-657. Retrieved from:

<https://www.ncbi.nlm.nih.gov/pubmed/22098423>

Appendix A

Community Approval

**Special Council Meeting
Wednesday, January 16th, 2019**

MOTION NO. 2019-13-264

Moved By: Thomas Cheechoo

Seconded By: Joe Cheechoo

To approve the following recommendations from the Health Committee:

1. 
2. 
3. 
4. The Health Committee recommends Justice Siedel, Master's of Indigenous Relations student to move forward with her project, Relocating for Specialized Care: Understanding First Nation Patient Experiences. The Health Committee would like Justice Siedel to present her Final Report once the project is completed.

Appendix B

Recruitment Posters

CALL FOR PARTICIPANTS

Justice Seidel, a Master's student in the Master's of Indigenous Relations Program at Laurentian University and a Moose Cree First Nation Member is seeking participants for her Master's thesis.

Her project explores the experience of First Nation patients in having to travel out of Moose Factory/Moosonee for health services.

ARE YOU?

A First Nations individual?

Have you travelled from Moose Factory/Moosonee for health services?

Over the age of 18?

Have health conditions that require many medical appointments?

Justice Seidel is seeking First Nations people from Moose Factory/Moosonee who have been relocated to urban hospitals (Kingston General Hospital, Timmins and District Hospital, Health Sciences North, etc.) for health services to speak about their experience. Participants will be required to sign a consent form and will receive \$50.00 to participate. The interview is 10 questions and will take approximately 30-60 minutes.

To sign up or learn more, contact:

Justice Seidel

(705)-920-0640

jseidel@laurentian.ca



**SCHOOL OF
INDIGENOUS RELATIONS**
NISHNAABE KINOOMAADWIN
NAADMAADWIN

Appendix C

Letter of Information



Appendix A: Letter of Information

Research Project:

Relocating for Specialized Care: Exploring First Nation Patient Experiences

LETTER OF INFORMATION

Introduction: Wahchay, my name is Justice Seidel and I am a member of the Moose Cree First Nation. I am currently completing my Master's degree from Laurentian University in the Master's of Indigenous Relations program. Over the years, I've heard the stories of my family members who are relocated from Moose Factory and Moosonee to hospitals in Kingston, Sudbury and Timmins for their health appointments or emergencies. I was also able to experience the relocation first hand as I escorted my grandpa, Abel Butterfly, to an appointment in Kingston. To complete the requirements of my program, I am working with researchers at Laurentian University to complete a thesis project.

Purpose of this study: The purpose of this study is to learn about the experiences of people from Moose Factory/Moosonee who have had to travel for health services. We are looking for ways to improve these experiences. We hope that the results of this project lead to better services for First Nations patients from the Moose Factory/Moosonee area.

What do we ask of you? We are asking you to sit with me and share the story of your experience of travelling to a larger, urban hospital for medical care. In general, we will talk about your experiences leading up to, during, and following the travel. We will also ask you for feedback on ways that medical relocations could be improved. Each interview will take approximately 30-60 minutes. The interviews will be recorded and transcribed. You will have the opportunity to look through the transcripts to make sure that there are no errors in the stories that are shared. You will also be compensated \$50.00 for your time during the interview process.

Study requirements: We are interviewing First Nations people who have been traveled from Moose Factory/Moosonee to a larger urban hospital for medical care within the last two years. Participants must be 18 years of age or older and live with more than one chronic condition.

What's in it for You? You will have the opportunity to share your stories and experiences with a goal of improving health services for community members. When the project is complete, we will share the results with you if you are interested in receiving a hard copy and there will also be a community information session sharing the findings.

Confidentiality: Your name and contact information will be kept confidential. We will remove your name from all transcripts, if you wish. We will store your consent form in a locked cabinet, the recording and transcripts of your interview will be stored electronically in a secure location that is password protected. Please note that during the interview, if you say you are planning to inflict immediate harm to yourself or others, I am required to report the incident. This

information will be provided to Moose Cree's Crisis Management and Support Worker, Joyanne Cheechoo.

Voluntary Participation: Participation in this study is voluntary. You may refuse to participate or withdraw from this study at any time, without consequence. You are in control of what stories and experiences you would like to share.

Questions: If you have any questions about how this study, or your rights as a research participant, you may contact the Laurentian University Research Office, telephone: 705- 675- 1151 or toll free at 1-800-461-4030 or email: ethics@laurentian.ca. You may also contact my supervisor, Dr. Jennifer Walker at jenniferwalker@laurentian.ca.

Additionally, if you have questions about the study itself, please contact me at jseidel@laurentian.ca. Please save this information for future reference.

Sincerely,



Justice Seidel, BSc (Hons)
Candidate, Master of Indigenous Relations

Appendix D

Consent Form



Appendix B: Consent Form

Research Project:

Relocating for Specialized Care: Exploring First Nation Patient Experiences

INFORMED CONSENT

Consent to Participate

I have read and understand the Letter of Information explaining the nature of the study and I agree to participate. All my questions have been answered to my satisfaction.

I agree to be audio-recorded and I give consent to the release of the transcripts of those recordings.

I am aware that the transcripts will be kept for 5 years and any information that may personally identify me will not be associated with the transcript.

Participant Name (printed): _____

Signature of Participant: _____ Date: _____

In my opinion, the person who has signed above is agreeing to participate in this project voluntarily and understands the nature of the study and the consequences of participation in it.

Signature of Interviewer: _____ Date _____

ORAL CONSENT FORM

For participants who choose to give oral consent and not written consent:

In my opinion, the individual: _____ is agreeing to participate in this project voluntarily, and understands the nature of the project and the consequences of participation in it.

Signature of Interviewer: _____ Date: _____

Location: _____ Time: _____

Appendix E

Semi-Structured Interview Guide



Appendix C: Interview Guide

Research Project:

Relocating for Specialized Care: Exploring First Nation Patient Experiences

Interview Code: _____

Date: _____

Age: _____

Time: _____

INTERVIEW GUIDE

1. Can you tell me about your health and any chronic conditions you may have?
 - a. Prompt: How long have you had these conditions?
2. What health services do you use in the community for your health conditions?
 - a. Prompt: What health services do you access that are not available in the community?
 - b. Prompt: Health services could be an appointment, a surgery, or an emergency.
3. Thinking back to a time when you had to travel for health services out of town, where were you travelling for your appointment? How did you get there?
4. What information and support did you receive about your travel and your appointment? Did you feel well prepared?
5. Did you feel like you were supported while you were away for your appointment?
 - a. Prompt: Were you provided an escort for your appointment?
6. What was your experience during your appointment?
 - a. Prompt: Did you feel like your doctor understood your perspective as a First Nations person?
7. While you were in a larger city for your medical appointment, were there any challenges you faced?
8. Are there positive aspects about travelling to a larger city for health services that you enjoy?
9. What kinds of things could be improved when community members have to leave Moose Factory or Moosonee for medical appointments?