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“We Are Bridging That Gap”: Insights from Indigenous Hospital Liaisons for Improving Health Care for Indigenous Patients in Alberta

Link, Claire MacKinnon

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“We Are Bridging That Gap”: Insights from Indigenous Hospital Liaisons for Improving Health
Care for Indigenous Patients in Alberta

by

Claire MacKinnon Link

A THESIS

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Abstract

This thesis explores the insights of five Indigenous Hospital Liaisons working in Alberta Health Services hospitals to improve health care for Indigenous patients. Indigenous people in Canada often encounter difficulties and obstacles when accessing health care. Previous studies have described the negative experiences that many Indigenous people encounter within hospitals and other health care facilities. Limited research in Alberta prevents an understanding of context-specific barriers that may exist. Additionally, the insights of Indigenous Hospital Liaisons are a new area of research. These frontline employees work directly with Indigenous patients to help them navigate barriers and ultimately improve their hospital experiences. This research uses a strength-based approach to highlight the dedication that Indigenous Hospital Liaisons have to Indigenous patients and provide a more positive image of Indigenous people. In addition to pointing out barriers they believe are commonly encountered by Indigenous people in Alberta, the Indigenous Hospital Liaisons in this research highlight existing resources that can benefit Indigenous patients. They also share their suggestions for changes that may improve hospital experiences for Indigenous people. The findings of this research provide a welcome contrast to the mass of negative and often deficit-based research that dominates the Indigenous health literature and suggest a more positive and optimistic view of the future of health care for Indigenous people in Alberta. Specific recommendations are provided based upon the findings and suggestions for future research involving Indigenous Hospital Liaisons are discussed.

Keywords: Indigenous health, health care experiences, health care access, strength-based research

Preface

This thesis is original, unpublished, independent work by the author, Claire MacKinnon Link. The findings reported in Chapter 4 and Appendix D were covered by Ethics Certificate number REB19-0634, issued by the University of Calgary Conjoint Faculties Research Ethics Board for the project “Improving Health Care for Indigenous Patients at Acute Care Sites in Alberta: Insights from Frontline Indigenous Hospital Liaisons” on October 16, 2019.

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Chapter 1: Introduction

In September 2008, Brian Sinclair, an Ojibway man living in Winnipeg, went to the Health Sciences Centre emergency department to receive treatment for abdominal pain and other symptoms. He arrived just before 3pm and spoke with the triage aid.¹ Due to either an error made by the aid or for other still unclear reasons, a chart was not created for him and he was never triaged (Brian Sinclair Working Group 2017). The few medical staff members who noticed him as he waited believed that he had either been discharged or was simply taking shelter in the emergency department due to homelessness and/or intoxication. As he waited he vomited multiple times and bystanders alerted a security guard and a student nurse but no staff members gave him medical care (Brian Sinclair Working Group 2017). After 34 hours in the waiting room Brian Sinclair passed away from what was later found to be a treatable bladder infection (Brian Sinclair Working Group 2017; Gerster 2018). A waiting room bystander alerted security after noticing Sinclair and fearing that he was dead. Despite his visibility in the waiting room, staff members had ignored Brian Sinclair and did not administer care that could have saved his life.

The circumstances surrounding his death were not investigated by Winnipeg Police Services until two years later and the investigation concluded that no criminal charges should be laid. Indigenous community members, organizations, and Sinclair's family members lobbied the Manitoba government for a public inquiry² but the government opted for an inquest that would focus specifically on Brian Sinclair's death rather than the wider systemic issues endured by Indigenous people seeking medical services (Brian Sinclair Working Group 2017).

¹ Triage is the process used to determine the order of treatment for patients, often in emergency departments. It is based on the severity and urgency of patients' ailments (see The Daily Scan 2018 for more information: <http://thedailyscan.providencehealthcare.org/2018/11/emergency-room-triage-how-does-it-work/>).

² The wider scope of a public inquiry could have examined the larger issues of what the public viewed as substandard medical treatment, and could have explored the barriers encountered by Indigenous people when accessing health care.

Brian Sinclair's death drew attention to issues with emergency department practices rather than issues of racism and discrimination that Indigenous people face in health care settings. However, as the Brian Sinclair Working Group points out, "in the time that Mr. Sinclair was at the Health Sciences Centre Emergency Department, 150 other patients came to the ED [Emergency Department]. All 150 of them were triaged and all were treated or voluntarily left without being seen" (2017:3). Brian Sinclair, an Indigenous man who was assumed to be drunk or homeless, was ignored and this suggests his experience was not merely the result of a busy emergency department.

Eight years later in February 2016, Kimberly Gloade, a Mi'kmaq woman from the Burnt Church First Nation in New Brunswick, was taken to the McGill University Health Centre emergency department in Montreal with severe abdominal pain (Fennario 2018). She was triaged as a low priority patient (Feith 2018). She did not have her health care card as it had recently been stolen along with her purse. The admissions nurse told her she would be billed for any treatment she received and that the total would be over \$1,000. As a result, she left the emergency department just 23 minutes after arriving. Emergency department staff are required to inform patients who require care that they can still receive treatment without a health card, but no staff members explained this policy to Kimberly (Feith 2018; Laframboise 2018). She passed away six weeks later from heart failure and cirrhosis of the liver (Laframboise 2018). In the inquiry following her death the coroner noted that while the damage to her liver had been too severe to be fully treated at the time of her emergency room visit, she was not, "[offered] the minimal accompaniment that decency requires in the face of death from a society worthy of its name." (Feith 2018). Kimberly Gloade should have received treatment to help her deal with her pain and enhance her comfort as her condition progressed. According to her family, the care that should have been provided would

have considerably eased the, “pain and suffering” that she experienced in the weeks leading up to her death (Stevenson 2017).

Since Gloade’s death the McGill University Health Centre has implemented measures to ensure that incidents like this do not happen again. A standardized script was created for staff to inform all patients that they can receive care even if they do not have a health card. Additionally, a policy was implemented to re-evaluate patients who wish to leave the facility prior to receiving treatment, to determine if this is safe or not. Therefore, patients in serious medical distress can be made aware of the severity of their situation before choosing to leave (Feith 2018; Fennario 2018).

Despite concerns from Gloade’s family that her treatment in the emergency department was the result of discrimination, as she was visibly Indigenous and also struggled with homelessness, the hospital director dismissed these concerns and stated that racism was not a factor in the situation. According to a spokesperson for the hospital, “no one is turned away” from the emergency department (Feith 2018). Despite this claim, Kimberly Gloade was effectively turned away by being placed in a position where she had to decide whether to incur an expense for medical treatment that she could not pay, or forgo treatment. She chose the latter, with no protest from medical staff, and died an early and painful death as a result.

Later that year Hugh Papik, an elder in Aklavik, Northwest Territories, suffered a massive stroke at his care home in August 2016. His niece Maggie Papik arrived to find him lying on the floor and was told by staff that he was drunk. She accompanied him to the local Aklavik Health Centre where nurses also believed him to be drunk and refused to perform a physical exam. Six hours passed before he was finally transported to the nearest hospital in Inuvik where doctors confirmed that he had suffered a stroke. He was then sent to Yellowknife Stanton Territorial

Hospital for a computed tomography (CT) scan³ to assess whether he had suffered brain damage. By this time it was too late and Hugh Papik was pronounced brain dead upon arrival at the Yellowknife hospital (Bird 2016; Blake 2018; CBC News 2016). A week later, his family made the difficult decision to remove him from life support systems. Following his death Maggie Papik went public with the story of her uncle's mistreatment by care workers and nurses in Aklavik. Her actions brought to light the discrimination that Indigenous people face within the health care system. She stated that since going public other Indigenous people (primarily those living in Nunavut) whose family members had similar experiences had reached out to her. Some mentioned misdiagnoses by doctors while others had illnesses that were ignored altogether (Burke 2018).

The Northwest Territories' Minister of Health and Social Services ordered an external investigation following the death of Hugh Papik, which the minister deemed a "critical incident" (Burke 2018). The investigation, led by Cree doctor Marlyn Cook, resulted in a series of recommendations being released by the Northwest Territories government in February 2017. Her recommendations included the development of mandatory cultural safety training for all health care workers. Unfortunately, the report was not released to the public and Maggie has not received updates on which recommendations, if any, have been implemented (Burke 2018).

These stories inspired me to focus on gaining a deeper understanding of Indigenous peoples' health care experiences for my research. The stories described above involve Indigenous people who attempted to access needed health care but were ignored by staff whose job it is to take care of people with health issues. Each passed away in what one can only assume was extreme discomfort. By being Indigenous, these individuals were viewed by health care professionals as

³ A CT scan is a computerized imaging procedure that uses multiple X-ray images taken from different angles to produce cross-sectional images of bones and tissues. They provide more information than standard X-ray images and can be used to detect internal damage and bleeding (see National Institute of Biomedical Imaging and Bioengineering 2019).

less deserving of care than other patients. These cases demonstrate that Indigenous people face barriers to accessing and receiving health care as a result of discrimination⁴ that mainstream Canadians are less likely to face. I initially planned to focus my research on identifying the barriers that Indigenous people in select Alberta hospitals encounter by speaking with individuals whose job it is to help patients navigate health care and ensure that their needs are met.

Colonization and its Impact on Indigenous Peoples' Health

The lasting effects of colonization continue to create challenges for Indigenous people and negatively impact their health and health care access. Colonization refers to the period in history when European colonizers came to what is now Canada and forcefully took control of the land and the Indigenous people who inhabited it (Frideres 2016). The history of colonization cannot be shared here in full, however two colonial events are discussed below to provide context for the current health disparities of Indigenous people in Canada, and their health care experiences. The events discussed are the *Indian Act* and the Indian Residential School system.

The Indian Act, the Non-Insured Health Benefits (NIHB Program), and Bill C-31

Established in 1876, the *Indian Act* and its amended forms remain official Canadian policy today.⁵ Although policies exerting control over Indigenous people became present soon after the colonizers and Indigenous people first made contact in the 1600s, the *Indian Act* cemented the control of the Canadian government and fundamentally changed the social organization of First Nations peoples (Frideres 2016). This legislation continues to exert considerable control over essential aspects of Indigenous peoples' lives, including health care. The *Indian Act* also

⁴ Discrimination refers to differential treatment of groups of individuals. Discrimination is often perpetrated against members of marginalized groups, such as racial minorities, gender minorities, and individuals of low socioeconomic status. Racism is a form of discrimination where discriminatory treatment is carried out against individuals of a certain racialized group, based on the belief that the racialized group is inherently inferior (Bishop 2015).

⁵ Please note that when using terms like "Indian Status" I am using the official terminology from the *Indian Act*. "Indian Residential Schools" is also official terminology.

effectively ingrained racism against Indigenous people into Canadian society by emphasizing differences between Indigenous people and the mainstream population, and legislating the need for Indigenous people to be controlled by the Canadian government. Although many of the explicitly racist policies have been removed from the amended version, (Browne, Smye and Varcoe 2005) many negative stereotypes of Indigenous people, embedded in Canadian society through the *Indian Act* and other colonial policies, continue to harm Indigenous people today. For example, studies have suggested that some health care providers hold stereotypical racist views of Indigenous people which negatively impact the care they provide to Indigenous patients (see Tang and Browne 2008).

The *Indian Act* in its current form applies specifically to First Nations and Inuit but also impacts non-Status First Nations and Métis peoples through their exclusion from the legislation. *R v. Daniels 2013* – and the reaffirmation following the federal government’s 2016 appeal (see SCC 2016) – officially determined that non-Status and Métis peoples will be included under the definition of Indian, and therefore be Status Indians who are eligible for federal benefits. However, the effects of this decision have not been fully realized at this time (Vowel 2016).

NIHB is one federal benefit that Status First Nations and Inuit peoples can access. This program provides additional health coverage to cover services that are not covered under provincial health care systems. Health care provision is explicitly mentioned in Treaty 6; historical documents show that medical agreements were part of other treaty negotiations as well, however these agreements were not included in the official treaty text (Loyer and Small Legs 2014).

NIHB covers services like mental health and counseling, dental work, prescription drugs, and medical supplies and equipment (Government of Canada 2020a). Based on this description, the program sounds beneficial for qualifying First Nations or Inuit patients. However, the program

is fraught with issues, such as a failure to effectively communicate policy changes and confusion regarding patient coverage benefits, among others (Morrison 2015).

Significant cuts to NIHB made in the 1990s resulted in confusion for patients and health care providers, and further changes continue to take place today (Loyer & Small Legs 2014). A recent survey found that among First Nations adults living on-reserve, NIHB-related issues were among the most commonly reported barriers to accessing health care (FNIGC 2018b). Issues included services not being covered by NIHB, coverage being denied, and confusion as to what services were covered. This discussion suggests that utilizing NIHB is not as simple as it seems. In addition to the aforementioned reasons, much of the NIHB program's complexity stems from the eligibility criteria. The *Indian Act* determines who qualifies as an "Indian" and therefore who is eligible for NIHB coverage.

Under the *Indian Act* (1876), there were numerous ways that First Nations people could lose their Indian Status. If a First Nations person wished to vote in a federal election they would have to give up their Status through a process known as enfranchisement (Government of Canada 2020b). If a First Nations person lived outside Canada for more than five years their Status was removed. One of the most damaging restrictions in Section 12(1)(b) stated that if a First Nations woman married a non-First Nations man, the woman's Indian Status was lost. The result of this restriction was that by 1985 (and the passage of Bill C-31 on April 17, 1985) there were only about 350,000 First Nations women who still held Indian Status (Bourassa, McKay-McNabb and Hampton 2004).

Bill C-31 made it possible for First Nations people who had been enfranchised to regain their Indian status. However, not everyone was eligible and the process of applying for Status was – and still is – long and complicated (Bourassa et al. 2004). The result is that even today many

First Nations people are unable to regain Indian Status, therefore preventing them from accessing NIHB coverage. The inability to access this coverage has negative health impacts for many non-Status people. Métis people also cannot access this coverage. Without NIHB, non-Status and Métis peoples must pay out of pocket for health services like prescription drugs. Many people cannot afford to pay for these services, as Indigenous people today face higher rates of unemployment and poverty than the mainstream population. This is the result of racism and discriminatory practices which were entrenched in Canadian society through the *Indian Act* and other colonial policies (Bent, Havelock and Haworth-Brockman 2008; Browne et al. 2005). It has also been suggested that an inability to regain Status has negative mental health impacts for non-Status people, who may feel distressed at their seeming lack of rights compared with Status individuals (Bent et al. 2008).

The next section explores another colonial policy that most Canadian readers should be familiar with due to the lasting trauma it caused: the Indian Residential School System.

The Indian Residential School System

The residential school system began in Canada in the seventeenth century and became widespread in the mid-nineteenth century. The last school closed in 1996 (Vowel 2016; Wesley-Esquimaux and Smolewski 2004). While the official goal was to assimilate Indigenous children into Canadian society, this does not reflect the brutal reality of residential schools. The Truth and Reconciliation Commission used the term “cultural genocide” to better convey the horrific reality of these schools (TRC 2015). The legacy of residential schools is so large and traumatic because it continues to affect not only the survivors, but their families including their children, grandchildren, and other relatives (Hackett, Feeny and Tompa 2016; Reading and Wien 2013).

The term “historic trauma transmission” has been used to discuss the intergenerational impact of residential schools on Indigenous people. This term describes, “cumulative emotional and psychological wounding across generations” (Eyaa-Keen Healing Centre 2015). In the context of residential schools this refers to unresolved trauma and pain that is passed from generation to generation, with the result that the trauma created by the residential school system continues to collectively impact Indigenous people (Wesley-Esquimaux and Smolewski 2004).

A 2018 survey of First Nations adults living on-reserve showed that 62% of those who attended residential schools believed it had a negative impact on their health (FNIGC 2018a). Additionally, respondents who either attended or whose parent attended residential school self-reported poorer health than those who stated they were not impacted by residential schools. A 2016 study looked at the intergenerational effects of residential schools on self-rated health and measurable mental health outcomes including mental distress, suicidal ideations, and suicide attempts (Hackett et al. 2016). The likelihood of experiencing all of these outcomes was higher for Indigenous people living off-reserve who had at least one family member who attended residential school. These participants also rated their overall health lower than did participants without a familial connection to residential schools (Hackett et al. 2016). Indigenous people may also feel generally uncomfortable in health care settings due to reminders of residential schools triggered by institutional settings like hospitals (Reading and Wien 2013).

Over time, fewer people will have personally attended residential school. However, the effects will continue to be felt in Indigenous families for generations to come. A 2018 survey found that of First Nations people living on-reserve, almost 75% of adults had either attended or had a parent or grandparent who attended residential school and nearly two-thirds of youth had a parent or grandparent who attended (FNIGC 2018a). This means that the intergenerational effects of

residential schools will continue to negatively impact the health of Indigenous people. This needs to be recognized so that solutions can be found to minimize the harm that these lasting impacts have for Indigenous peoples' health.

The Central Problem

Indigenous people in Canada experience poor health outcomes relative to the non-Indigenous Canadian population (Dell et al. 2015; Reading and Wien 2013). Off-reserve Indigenous people generally rate their health lower than non-Indigenous people in the same age group. They typically report poorer mental health and a higher prevalence of chronic conditions than do non-Indigenous people (Kelly-Scott and Smith 2015). First Nations people living on-reserve also have a high prevalence of chronic conditions, with diabetes, high blood pressure, and arthritis having high frequencies (FNIGC 2018a). Diabetes is estimated to occur three to five-times more frequently on reserves than in the general population (Turin et al. 2016). Respiratory illnesses are another concern, with children on reserves experiencing higher rates of asthma and allergies than children in other areas (Pahwa et al. 2017). These trends are seen across Canada.

In Alberta, Indigenous people experience higher rates of chronic conditions and mental health issues than the mainstream population (Arriagada 2016; Crowshoe et al. 2018). Research suggests that the risk of diabetes, in particular, is considerably higher for Indigenous people, compared to non-Indigenous Albertans (Turin et al. 2016). One local study of First Nations and non-Indigenous men and women suggested that, at age 20, the lifetime risk of diabetes was 20% higher for First Nations men and nearly 40% higher for First Nations women compared to men and women in the mainstream Alberta population (Turin et al. 2016).

The most recent data from Statistics Canada shows that Indigenous people in Alberta generally rate their health lower than non-Indigenous Albertans: About 53% of Indigenous people

living off-reserve rated their health as excellent or very good, compared with almost 63% of non-Indigenous Albertans (Arriagada 2016). Additionally, Indigenous people were more likely to have at least one chronic condition such as arthritis, asthma, or high blood pressure. For example, 65% of Inuit respondents, 62% of off-reserve First Nations respondents, and 56% of Métis respondents reported chronic illness compared to 53% of non-Indigenous respondents (Arriagada 2016).

Limited access to health care contributes to the health disparities experienced by Indigenous people across Canada (FNGIC 2018; Reading and Wien 2013). Indigenous people living off-reserve are less likely to have a family doctor than are non-Indigenous people, decreasing their access to basic health care (Reading and Wien 2013). Transportation issues have also been identified as barriers that Indigenous people encounter when accessing health care.

As the stories of Brian Sinclair, Kimberly Gloade, and Hugh Papik illustrate, when Indigenous people *are* able to access health care facilities, they may not be treated adequately or receive the care they need. A recent study in Toronto found that over 30% of Indigenous participants reported experiencing discrimination from a health care provider and that individuals who had experienced discrimination were significantly more likely to have unmet health needs (Kitching et al. 2019). This suggests that even if Indigenous people are able to access health care they may not receive sufficient treatment. As discussed, discrimination against Indigenous people is rooted in the discriminatory policies put in place by the *Indian Act* and other legislation that led to systematic mistreatment of Indigenous people.

Access to and treatment within health care are examples of social determinants of health, which are non-biological factors that impact health (Greenwood, de Leeuw and Lindsay 2018). Social determinants of health include basic necessities of life such as: food, shelter, water, clothing, education, employment, and income (Greenwood and de Leeuw 2012; Reading and Wien 2013).

Additional factors such as self-determination, cultural continuity, and racism are also important to consider, especially when trying to understand the health of Indigenous people in Canada (Reading and Wien 2013). Although social determinants of health impact all individuals, historical and contemporary impacts of colonization require these factors to be considered separately for Indigenous people (Greenwood et al. 2018; Hackett et al. 2016; Reading and Wien 2013).

As mentioned, access to quality health care has been identified as a key social determinant of health for Indigenous people (Gracey and King 2009; Greenwood et al. 2018; Reading and Wien 2013). While physical barriers to health care, like living in a remote community or lacking transportation, present challenges for many Indigenous people, an understanding of access needs to go beyond physical definitions to consider additional barriers (Reading and Wien 2013).

Non-physical barriers to accessing health care include discriminatory treatment and a lack of individual trust in health services leading to avoidance, among others (Berg 2018; Reading and Wien 2013). As more Indigenous people move to urban centres non-physical barriers may be particularly salient, although physical barriers will continue to cause difficulties. According to recent data, Indigenous people make up 11% of the population of Winnipeg, 5% in Edmonton, 3% in Calgary, and about 1% in Vancouver and Toronto (Arriagada 2016; Chernikova 2016; Kelly-Scott 2016; Kelly-Scott & Arriagada 2016). These are sizeable percentages given the total populations of these urban centres are quite large. Sixteen percent of the total Indigenous population in Canada lives in Alberta, making up 6% of the total Alberta population. Over 50% of First Nations individuals live off-reserve and 35% of the total Indigenous population in Alberta resides in large population centres, with 28% residing in Edmonton and another 15% in Calgary (Arriagada 2016). With a growing Indigenous population Alberta's health care provider – Alberta

Health Services – must try to understand the barriers that Indigenous people face when accessing health care.

The Truth and Reconciliation Commission's (TRC) Calls to Action include seven priorities directly linked to health, which are as follows:

1. *Closing the health gap between Indigenous peoples and the settler population,*
2. *Respecting the unique health needs of Indigenous peoples,*
3. *Providing funding for healing centres to address harm caused by the residential school system,*
4. *Incorporation of Indigenous healing practices and collaboration with traditional healers and Elders in health care settings,*
5. *Increasing the number of Indigenous health care professionals,*
6. *Ensuring that Indigenous health care professionals are available in Indigenous communities, and*
7. *Providing culturally competent and appropriate care, and incorporating Indigenous health-specific training and information into medical and nursing education programs in Canada (TRC 2015).⁶*

These Calls to Action must be taken seriously to improve the health of Indigenous people.

Research such as this current study represents a small step in this direction.

Initial Interest and Research Problem

As a non-Indigenous researcher I understood that I needed to learn about Indigenous research practices to ensure that this research was done respectfully. Indigenous scholars like Margaret Kovach and Linda Tuhiwai Smith helped shape the research that I planned to do (see Kovach 2009; Tuhiwai Smith 2012). In studying the works of these scholars the idea of decolonizing research stood out to me, which is carried out with the primary goal of benefiting Indigenous people and highlighting Indigenous peoples' strength and resilience. However, the original project I had planned to do – which focused on identifying barriers that Indigenous people

⁶ For the unabridged wording of these and all other Calls to Action, refer to the report *Truth and Reconciliation Commission of Canada: Calls to Action* (2015). This report can be accessed at: http://trc.ca/assets/pdf/Calls_to_Action_English2.pdf

encounter in Alberta hospitals – did not fit with the principles of decolonizing research. How would describing barriers benefit Indigenous people or highlight their strengths?

I was able to find a new inspiration for my research through my volunteer work with Alberta Health Services, which I have been doing for several years. One of my positions provided me with the opportunity to work with the Indigenous Health Program to enable more Indigenous patients to attend the weekly smudging ceremony⁷ at one Alberta hospital.

The Indigenous Health Program is a department within Alberta Health Services dedicated to providing high quality and appropriate health care to all Indigenous people in Alberta (AHS 2020a). This program was created in 2009 through increased development of an existing program, the Aboriginal Diabetes Wellness Program, which was started in 1996. The expansion of this program led to the Indigenous Health Program becoming a province-wide Alberta Health Services initiative (Royal Alexandra Hospital Foundation 2015). The program continues to expand and offer new services to meet the needs of Indigenous people in Alberta.

The Indigenous Health Program aims to provide patient-centred care and ensure that health care is accessible and equitable for all First Nations, Métis, and Inuit peoples living in Alberta (AHS 2020a). The program works directly with Indigenous communities and patients and is guided by the Wisdom Council, an Indigenous-led advisory council formed in 2001. It provides recommendations to Alberta Health Services regarding health programming and services necessary for meeting the needs of Indigenous people in Alberta (AHS Wisdom Council 2019).

As a volunteer I visited Indigenous patients who expressed interest in attending a weekly smudging ceremony and reminded them of the time and place and assisted patients with mobility

⁷ Smudging is a traditional Indigenous practice where individuals cleanse themselves using the smoke of burned medicines, such as sage or cedar. The weekly ceremony usually involves a prayer song as well, led by the smudge facilitator.

issues. This position also gave me the privilege of attending the smudge each week. Before taking this position I had no idea that many Alberta hospitals host this weekly smudging ceremony for patients, family, staff, and all others who wish to attend.

The positive impact of this resource for many patients with whom I attended the smudge was clear and I started to wonder what other resources were available for Indigenous patients. Everything came together in June of 2019 when the decision was made (after consultation with my supervisor and a manager within the Indigenous Health Program) to combine the original project about identifying health care barriers in Alberta with an exploration of programs and resources available to Indigenous patients in Alberta hospitals.

The Indigenous Health Program manager that I spoke to suggested I work with specific employees called Indigenous Hospital Liaisons. These individuals are variously called Indigenous Health Liaisons and Aboriginal Liaison Workers depending on the site. All participants identified themselves as Indigenous Hospital Liaisons, so this term is used throughout this thesis.

Purpose and Research Questions

The purpose of this study and the research questions were determined through discussions with an Indigenous Health Program manager and the five initial study participants.⁸ Four research questions were developed. To answer these questions I carried out primary data analysis on each participant's individual interview transcripts. Throughout the data analysis process I tried to keep in mind the principles of decolonizing research. This is discussed in more detail in Chapter 3.

The four research questions were determined based on several factors. First, questions were developed through discussions with individuals working in the Indigenous Health Program. It was

⁸ The five initial participants were all Indigenous Hospital Liaisons. A sixth participant who works as a Traditional Wellness Worker was asked to participate after discussions with other participants. However, this sixth participant was not part of the initial project discussions.

these discussions that shaped this project and made it possible, and I wanted to ensure that the research questions reflected the ideas of these employees.

Second, I based my research questions on the thoughts and questions I had after reviewing the existing literature on the topic of Indigenous people and health care in Canada.⁹ I wanted to try and fill gaps in the literature as well as focus on key themes that had not yet been looked at in the context of Alberta hospitals.

Finally, I wanted to make sure that my questions focused on elucidating issues as well as highlighting solutions and positive aspects of health care for Indigenous people in Alberta. The Indigenous health literature tends to focus on negativity and this ultimately does not lead to solutions (Strega and Brown 2015). Indigenous communities are also interested in hearing about initiatives with positive impacts, instead of only focusing on barriers. In a study conducted by Hole et al. (2015), the authors stated that their Indigenous community partners continuously expressed the importance of exploring both positive and negative health care experiences, noting that positive and negative critiques are relevant and important to Indigenous communities (2015:1665). I did not want to approach this study with the intention of only exploring negativity.

Taking the above concerns into consideration, I decided on four research questions:

1. What is the role of Indigenous Hospital Liaisons in hospitals within Alberta Health Services?
2. What do Indigenous Hospital Liaisons identify as common barriers that Indigenous patients encounter when accessing health care in Alberta?
3. What existing resources or services do Indigenous Hospital Liaisons highlight as beneficial to Indigenous patients?
4. What additional changes would Indigenous Hospital Liaisons recommend to Alberta Health Services to improve the experiences of Indigenous patients?

⁹ A review of the existing literature is provided in Chapter 2.

A recent review of Alberta Health Services resulted in cuts being recommended to potentially decrease funding by over one billion dollars (Fieldberg 2020). It is unclear exactly what these cuts will mean for Alberta Health Services however there will inevitably be changes. In light of this, it is especially important to highlight the success stories of the Indigenous Health Program and Indigenous Hospital Liaisons to ensure these services are protected from funding cuts.

This study involves interviews with five Indigenous Hospital Liaisons and one Traditional Wellness Worker, all of whom self-identified as Indigenous and are currently employed by Alberta Health Services. Indigenous Hospital Liaisons typically work in hospitals and help patients with any concerns they have during their hospital stay. This includes helping patients meet their cultural needs, communicate with staff members, and access additional resources (AHS 2020b). Traditional Wellness Workers, who may be referred to as Cultural Helpers or Traditional Wellness Counselors depending on the site, work at multiple care sites and provide visitation and cultural services to patients (Berg 2018). Traditional Wellness Workers and Indigenous Hospital Liaisons have distinct roles, however both work directly with Indigenous patients.

The overall purpose of this research was to explore the role of Indigenous Hospital Liaisons; identify the barriers they believe are common for Indigenous patients; highlight existing beneficial resources for Indigenous patients; and share their recommendations to improve health care for Indigenous people in Alberta. This research contributes a unique perspective to the Indigenous health literature by focusing on the insights of Indigenous health care employees working directly with Indigenous patients to improve their experiences.

Thesis Organization

This thesis is organized into five chapters: Introduction, Literature Review, Research Methodologies, Research Findings, and Conclusion and Recommendations. This first chapter

introduced the topic and provided an overview of my inspiration. I provided brief contextual information about colonization and the health of Indigenous people in Canada. I recognized my position as a non-Indigenous researcher and introduced how principles of decolonizing research informed this work. The purpose of the research was discussed and the research questions were listed, along with my rationale for selecting the questions.

In Chapter 2, I provide an in-depth review of the existing literature on the topic of Indigenous people and health care. I highlight key findings in two different types of studies. I conclude the chapter by discussing gaps in the literature that this current study aimed to fill.

Chapter 3 discusses the details of my research methodologies, beginning with how decolonizing theory informed the research. I detail the study design, including a description of the sample, an explanation of how participants were chosen and an overview of the data collection and analyses processes. I conclude the chapter by discussing one limitation of this study.

Chapter 4 is the largest chapter and shares the findings of this research. The findings were determined through analyzing participants' interviews to answer my research questions. The chapter is divided into several sections, each of which presents findings relevant to one of the research questions. This leads into the final chapter.

The final chapter, Chapter 5, summarizes the key findings of this research and shares two groups of recommendations that I think would benefit Indigenous people in Alberta within health care settings. These recommendations are based on the insights of participants which formed the findings of this research. I then discuss possibilities for future research before offering a brief conclusion to this study.

Chapter 2: Literature Review

This chapter provides a review of existing literature on the topic of Indigenous peoples' health care experiences in Canada. The selected literature identifies common barriers and provides examples of effective health interventions for Indigenous people. I highlight gaps in the literature before concluding the chapter with a discussion of how I intended to fill these gaps, and how the literature collectively shaped the focus of this current research.

Choosing the Literature

I selected a relatively recent collection of studies from the Canadian context for this review. The studies are mainly qualitative in design, with one quantitative study included to complement another study. Two types of studies related most to my research goals. The first focused on Indigenous patients' experiences and barriers they encountered when accessing health care. These studies primarily included patient insights, with limited focus on staff perspectives. The second explored interventions and programs that aimed to improve Indigenous patients' experiences. These studies often cited the enhancement of cultural safety, a term that is discussed next.

Cultural Safety

Cultural safety is mentioned in many studies and is becoming increasingly popular for Indigenous health researchers. This term emerged from nursing literature in New Zealand and is often discussed in relation to providing health care to diverse groups, especially Indigenous people, worldwide. Culture is defined broadly, referring to "the beliefs and practices common to any particular group of people," meaning that culture is not always linked to a specific ethnic group (Nursing Council of New Zealand 2012:13; Papps and Ramsden 1996). Safety is defined in relation to the delivery of health services by the health care provider. Care is safe if it is respectful in regard to a patient's culture and unsafe if it is demeaning, disempowering, or damaging to the

patient and/or their cultural identity (Nursing Council of New Zealand 2012; Papps and Ramsden 1996). Cultural safety requires health care providers to reflect on their own culture and associated power dynamics in relation to the culture of their patients.

A 2013 National Collaborating Centre for Aboriginal Health report explained cultural safety by discussing similarities and differences between it and other culturally-focused models, specifically cultural awareness, sensitivity, and competency (Baba 2013). Cultural awareness is the first step and means that health care providers acknowledge patients' cultural differences. Cultural sensitivity goes further and involves acknowledging and respecting those differences. Cultural competency focuses on ways that health care professionals can provide effective care to patients of different cultural backgrounds. Finally, cultural safety goes beyond cultural competency to recognize the effects of colonization, institutional racism,¹⁰ and other processes relevant to health care (Baba 2013). Cultural safety is becoming the preferred model in health care because it moves beyond recognizing differences to recognize underlying inequalities and power imbalances that negatively impact health care for Indigenous patients.

There are different models of cultural safety. Perhaps the most widely accepted is the Ramsden model, developed by Māori nurse Irihapeti Ramsden. A key aspect of this model is that cultural safety is defined as an outcome of care where patients assess if cultural safety was met (Ramsden 2002). This gives power to people who often feel powerless in health care, which may be especially true for Indigenous patients. Ramsden puts this clearly:

The enactment of Cultural Safety is about the nurse while, for the consumer, Cultural Safety is a mechanism which allows the recipient of care to say whether or not the service is safe for them to approach and use. Safety is a subjective word deliberately chosen to give power to the consumer (2002:6).

¹⁰ Institutional racism is a form of systemic racism that refers to policies and/or practices built into the operation of existing institutions, such as health care systems. These practices result in the exclusion of certain racialized individuals and groups, regardless of whether individuals working in the institution intend to discriminate or not (Alberta Civil Liberties Research Centre 2020).

That is, health care professionals are responsible for acting in a culturally safe way and patients determine if this is achieved. Cultural safety is increasingly being discussed within Alberta Health Services and is being implemented in their research and policy discussions (Berg 2018). Alberta Health Services is the first and largest fully integrated health care system to operate province-wide, resulting from the integration of 12 formerly separate provincial health entities in 2008 (AHS 2020c). While other provinces have multiple entities in charge of health care delivery, Alberta is unique in that Alberta Health Services delivers health care for the entire province. This single system means that cultural safety discussions and/or initiatives can impact the entire health care system, which may help to improve health care for Indigenous people in Alberta.

Patient Experiences in Health Care Settings

The studies included in this section discussed Indigenous patients' experiences in different Canadian health care settings. For the purposes of this review an experience qualifies as anything that happened to a patient, including interactions they had and emotions they felt, when they were accessing health care. An experience could be that a patient felt discriminated against; that they were refused care; or that they felt satisfied with the care they received, as examples. Most studies did not provide details about patients' health conditions, aside from those necessary to understand their experiences. The studies of this type grouped patients' experiences into categories based on similar themes, specifically: the types of barriers or issues that patients encountered when accessing health care and any positive experiences that participants shared.

Goodman et al. (2017) spoke with 30 Aboriginal people¹¹ who were or had previously been illicit drug and alcohol users, living in the inner city of Vancouver. Participants were asked to

¹¹ The studies discussed here variously use the terms "Indigenous" and "Aboriginal". I use the terms used by the authors and participants. Indigenous and Aboriginal will be used to reflect the terminology used in the specific study, and any quotes that are included will use the terminology of the participant.

describe their experiences in various health care sites including hospitals, local clinics, and safe injection sites.¹² The majority of participants described negative experiences, with only one positive example shared. The overall theme discussed by participants was that of being, “treated differently” (2017:5) by health care professionals. The authors provided specific examples to illustrate this. Some participants felt their health problems were trivialized by doctors. One participant described visiting a clinic to deal with a pain in his side. The doctor told him to, “walk it off” and he left (2017:7). The pain worsened and the participant later learned that he was suffering from a serious medical condition that required treatment. Another participant went to the hospital after having a seizure and believed that he was discharged prematurely, based on, “no sooner than [he] was out that [he] went into another seizure.” (2017:7).

Some participants explicitly stated that their mistreatment resulted from their being Aboriginal. One woman described an interaction she had at a safe injection site where the nurse was annoyed that she did not know how to safely inject herself. The nurse, “treated [her] like crap and [she] knows it was because [she is] Native.” (2017:5). Another participant shared that her mother had been scared to visit one hospital due to being consistently mistreated there, which the participant said was because her mother, “had HIV and because she was Native.” (2017:6). Whether or not the mistreatment of these patients occurred because they were Aboriginal, if a patient feels they have been discriminated against, their experience will be negatively impacted.

One positive experience was shared by a participant who appreciated his current doctor’s knowledge of addictions. The participant recalled how a previous doctor had sworn at him when he asked for medication to deal with seizures. He said, “the doctor did not put it together”, referring to the fact that his health complications were due to addictions (2017:8-9). It is concerning that the

¹² Safe injection sites are a type of harm reduction facility where illicit drug users can safely and legally use illegal drugs in a medical supervised setting (Canadian Centre for Addictions 2019).

only positive experience in this study was meaningful to the participant mainly because it was a contrast to the negative experiences he often had.

Hole et al. (2015) spoke with 28 Aboriginal participants regarding their experiences at a hospital in the British Columbia interior. While three positive experiences were included, the majority of experiences shared were negative. According to participants, the demeanor of nurses often changed when dealing with Aboriginal patients. They perceived nurses as friendlier and more caring towards non-Aboriginal patients. One participant commented that he sometimes saw nurses, “and they’re talking real nice to someone who’s not a Native and then they come in to [him] and their attitude changed.” (2015:1667). He noted that although not all nurses act this way, he encountered situations like this, “quite a bit.” (2015:1667).

Participants also discussed how their visibility as Aboriginal patients lead to them being ignored by staff. The authors commented that, “being ‘visible’ as [Aboriginal people] simultaneously produced them as ‘invisible’ to health care providers.” (2015:1669). One participant noted that she is usually not recognized as Aboriginal until she identifies herself. She commented, “I say I’m Aboriginal and then [the nurse] looks at me...I swear they’ve totally changed and then all of a sudden my care isn’t the same.” (2015:1669). Some participants explained that these issues occurred more frequently when nurses were busy or working long shifts, believing that this overworked environment contributed to mistreatment. This suggests that structural issues such as understaffing should be considered when trying to understand the factors that lead to negative health care experiences for Aboriginal people.

While negative experiences dominated this study, three positive experiences were shared. One participant described how staff members allowed her family to smudge in their hospital room following the death of a loved one. She commented that she, “thought it was just great that, uh,

staff members let [her family] do smudging in the room...and that [staff] respected what they wanted to do.” (2015:1666). Another participant was, “really impressed” with staff for accommodating a large number of Aboriginal family members and friends on a unit when a patient was at end-of-life (2015:1666). Positive experiences like these are encouraging and suggest that improvements are occurring to better assist Aboriginal patients and families.

Jacklin et al. (2017) explored health care experiences of Indigenous patients with Type II diabetes in British Columbia, Alberta, and Ontario. Some patients felt uncomfortable in health care settings due to these settings serving as painful reminders of colonial systems such as residential schools. Participants discussed how doctors with an authoritarian manner reminded them of their time in residential schools and made them feel, “tired of being told what to do.” (2017:E108). This reminder of residential school led some participants to lack trust in their doctor and even avoid health care facilities altogether.

The authors also shared examples of participants who interpreted their mistreatment as the result of racism. One participant described how he had travelled a long distance to undergo a biopsy in an urban hospital but was discharged without the procedure taking place and, “without an explanation” from staff (2017:E108). Another participant recalled going to the emergency department when bleeding from his mouth. According to the participant, medical staff thought he, “had been sniffing nail polish” and that this explained his symptoms (2017:E109), although a later blood test revealed that a serious health condition led to the symptoms. Both participants believed that their mistreatment would not have happened had they not been Indigenous.

Structural issues, such as a lack of family doctors and frequent staff turnover of local doctors, were also discussed as presenting difficulties for participants. Addressing the latter problem, participants commented that physicians would come to their communities for a short

time before moving on in search of higher pay. Other participants did not have a family doctor and had to go off-reserve to find a clinic, often meeting with a new physician at each appointment. Constantly meeting with new doctors can negatively impact a patient's care as the doctor may not be fully knowledgeable about their background and health history. Given the high rates of diabetes and other health conditions that Indigenous people in Canada experience, participants argued that more family doctors should be made available to Indigenous patients.

Tang and Browne (2008) and Browne et al. (2011) drew on findings from the same study which involved speaking with and observing Aboriginal and non-Aboriginal patients and staff members in an emergency department in a Western Canadian city. The focus of this study was patients who utilized the emergency department for primary care rather than urgent care.¹³ Many of the findings echoed those of the previously mentioned studies (Goodman et al. 2017; Hole et al. 2015; Jacklin et al. 2017). Thirty-four patient participants self-identified as Aboriginal and many were from the inner city and/or were active drug users. Multiple Aboriginal participants expressed that staff, particularly nurses and admitting clerks, treated them with a judgemental attitude. One participant disliked coming to the emergency department because he anticipated being mistreated, commenting that, "maybe it's because [he] looks like a street person...maybe it's because [he is] Native." (2011:338). Another participant noted that, "the staff have attitudes" but was unsure if it was "because [she is] a drug addict" or "because [she is] Native." (2011:338). The authors noted that while non-Aboriginal participants from the inner city also expressed concern over being judged by staff members, none worried that their race played a role in this.

Stereotyping was brought up by many participants as a significant issue. Tang and Browne (2008) provided multiple examples of Aboriginal participants being viewed as, "drunken Indians"

¹³ Primary care refers to services that enable individuals to manage their basic, every day health concerns. It is non-urgent care and includes services like family physicians and therapists (AHS 2020d).

(2008:115), which the authors noted is a colonial stereotype that retains a strong presence in Canada. Other studies touched on this (see Browne et al. 2011; Jacklin et al. 2017), however Tang and Browne explicitly discussed stereotyping as being rooted in colonization. They shared comments from a health care provider in the emergency department who believed that, “some [Aboriginal people] are going to be prone to alcohol abuse and drug addiction because it is in their genetic makeup at birth.” (2008:118). This type of thinking has no factual basis and suggests that some health care providers hold on to problematic myths and stereotypes about Aboriginal people. Another health care provider admitted that based on their experiences working in the emergency department, “[staff] tend to have a vision of every Aboriginal person having a drug and alcohol issue.” (2008:119). Other studies in this section shared only patients’ perceptions that stereotyping exists among some staff members, however by including staff perspectives Tang and Browne (2008) were able to confirm that stereotyping does occur.

Discussion

Taken together, these studies showed that Indigenous patients have negative experiences within health care settings seemingly quite frequently and that positive experiences are rarer. The main themes were reinforced in all of the studies, with stereotyping, indifference and judgement from staff members being the most common issues discussed. These issues are serious and need to be addressed in order to improve the health care experiences of Indigenous patients.

These studies mainly took place in British Columbia, although Jacklin et al. (2017) also included health care sites from Ontario and Alberta. The studies addressed different kinds of health care facilities, including hospitals, emergency departments, clinics, and safe injection sites. Despite the variety of settings, the same major themes and issues were discussed in all of the

studies. This suggests that similar issues persist across health care sites, and possibly across Canada, although research from other provinces is needed to confirm this.

While negative experiences dominated the studies, positive experiences were included when possible. Some of the practices that contributed to positive experiences were accommodation of Indigenous culture; accommodation of large numbers of visitors; and treating patients with genuine care, concern, and kindness. Although few positive experiences were shared, most of the studies had attempted to explore both positive and negative experiences. Even if this goal is not met, researchers should always intend to explore both aspects to ensure that strengths as well as problems are highlighted. Focusing only on negative elements is not productive and should not be the focus of research involving Indigenous people (Hole et al. 2015).

Health Interventions and Resources to Benefit Indigenous People

The studies included in this section described the results of health-based interventions intended to benefit Indigenous people in Canadian health settings.

Hadjipavlou et al. (2018) described the outcomes of a program that involved connecting Indigenous mental health patients with Elders at an inner city clinic. The results of the study were highly positive: all but one of the 37 patients interviewed reported their interactions with the Elders to be beneficial. Patients found comfort in speaking with the Elders and were able to build trusting relationships with them. One participant commented that, “I can talk and trust and not feel worried about [the elder] saying anything to anybody.” (2018:E612). The same participant noted that due to her experiences growing up, her trust, “has been broken in many areas” and that, “it is very hard for an Aboriginal woman or person to be open about a lot of things.” (2018:E612). These comments suggest that being able to build trust with the Elder was a significant achievement. The authors noted that multiple participants commented that they are generally mistrustful of health

care systems and providers, which starkly contrasted with the almost immediate trust they felt with the Elders.

Participants also discussed the positive impacts of spiritual services that the Elders provided. Unlike most mainstream health care providers, the Elders worked with participants to address their spiritual health as well as their mental health needs. This often involved incorporating traditional Indigenous practices such as prayer and smudging. One participant described the spiritual support of the Elders as “life-changing.” (2018:E613). Another participant commented that since meeting with the Elders they had started incorporating traditional practices into their daily home life by smudging frequently, a practice that was, “healing [their] soul.” (2018:E613). Participants noted that they did not feel they could speak to their doctor about spiritual health and were grateful that the Elders provided this support.

The authors noted that one reason participants were able to feel comfortable with the Elders was due to the shared history of colonization that all Indigenous people in Canada have in common. This enabled participants to strengthen their sense of belonging as Indigenous people. One participant commented that the, “common ground” shared with the Elders made it easy to talk about difficult topics such as residential school trauma (2018:E611).

Hadjipavlou et al. (2018) were part of a larger study that also involved a quantitative component. Tu et al. (2019) discussed the quantitative results, which measured participants’ mental health to quantify the impact of the Elder program. Two mental health measures were used – depressive symptoms and suicidal ideations – as well as emergency department use over a 12-month period. Depressive symptoms and suicidal ideations significantly decreased after participants had been enrolled in the Elder program for one, three, and six months (2019:277-278). Additionally, participants’ mental health-related emergency department visits decreased by 56%

and their total emergency department use decreased by 46%. The authors concluded that Elder programs like this may have measurable health benefits for patients. Quantitative findings that present measurable evidence of the health benefits of interventions may be especially useful for influencing health policymakers. Taken together with the qualitative findings from Hadjipavlou et al. (2018), it is clear that the Elder program had significant positive impacts for the participants.

Auger, Howell and Gomes (2016) discussed the results of a project in Vancouver, British Columbia that involved hosting seven workshops for Indigenous people to learn about traditional health care practices. The workshops were hosted by Indigenous Elders and knowledge keepers and focused on topics such as traditional medicines, ceremony, and identity, among others. The intent was to increase understanding of traditional health practices and how they could be used for preventative health care.

A key finding was that many participants placed significant value on traditional health practices and felt that these services should be made more accessible in mainstream health care systems. One participant noted that, “it’s always easier for [them] to go traditional first – because that connection seems to be right away” (2016:E395) while another participant commented that, “doctors today don’t know who we are...our traditional doctors knew us.” (2016:E395). The authors noted that traditional health care practitioners are often familiar with an individual’s personal history and may have worked with a certain family for many years. In contrast, mainstream doctors are unlikely to have this depth of knowledge, especially if patients lack a family doctor and rely mainly on walk-in clinics, which was the case for more than 40% of participants (2016:E395). Participants also liked the holistic approach of many traditional practices, which benefited their emotional and mental health in addition to their physical health. The authors noted that a barrier to providing traditional services is the, “mainstream rhetoric which

often denies the value or effectiveness of these practices” (2016:E395), suggesting that the rhetoric itself needs to change to make these services more available.

Auger et al. (2016) also presented policy recommendations based on participants’ suggestions. Increased funding for traditional health care and equitable pay for traditional health care providers were recommended to make these practices more available. Mandatory cultural competency training was also suggested, although the authors did not elaborate as to why participants felt this would help. Based on the findings it seems likely that this training could help change the dominant rhetoric within mainstream health care that invalidates traditional practices. Cultural training could help dismantle this rhetoric and make Indigenous patients feel more comfortable requesting traditional services.

It was encouraging to see actual policy recommendations in this study instead of generic suggestions. For example, “mandatory cultural competency training for all health care staff” (2016:E396) was a clear suggestion that policymakers could utilize. This ensured the research was action-oriented and was actively trying to improve health care for Indigenous people.

Cameron et al. (2014a) and Cameron et al. (2014b) discussed findings from an intervention project in Western Canada. Two Community Health Representatives (CHRs) from nearby First Nations were stationed in emergency departments at one urban and one rural hospital for six months. The CHRs accompanied Aboriginal patients who agreed to participate in the study as they spoke with the nurse. The CHRs stayed with patients until they were discharged and carried out brief interviews, and took notes based on their observations of patient-staff encounters.

According to Cameron et al. (2014a), CHRs are viewed as, “community health agents” in local Aboriginal communities (2014a:E2). This was not elaborated on, however a CHR position also exists within Alberta Health Services. CHRs work with patients, families and staff members

to ensure that Aboriginal patients receive adequate health care and are supported when accessing care, whether this is cultural support, translation services, or other types of support (AHS 2020e). These individuals typically self-identify as Aboriginal and may be stationed in communities, hospitals, or other health facilities, although their primary position is within an Aboriginal community (AHS 2020e). Their position places them in contact with Indigenous Hospital Liaisons, who are the focus of my research. Although their roles overlap in some ways, a key difference is that Indigenous Hospital Liaisons work within acute care sites in urban, and some rural, settings instead of being based in a community.

The authors discussed multiple benefits of having CHRs present in the emergency department. Enhanced communication with medical staff was a useful service that the CHRs provided. Both CHRs in this study were fluent in a local Aboriginal language and provided literal translation services for patients who spoke limited English (2014a and 2014b). One participant discussed how she had visited the emergency department before the CHR initiative began and could not understand the medical jargon and other, “high words in English” that staff members used (2014a:E9). The participant spoke Cree and was grateful that the CHR did as well, as it enabled her to gain a better understanding of what the doctor and other staff members told her during her visit. In addition to literal translations, the CHRs also had a strong understanding of medical terminology and procedures and were able to put this information in simpler terms to aid in patients’ understanding.

One participant commented that Aboriginal patients are often accompanied by a family member or other community member who can help with translation. However, family members are unlikely to be familiar with medical terms, making translation difficult. Additionally, family members may be, “shy or scared to say something wrong and be laughed at” (2014a:E9) and may

not ask for clarification from staff members. The authors did not speculate as to why the participant believed Aboriginal people anticipated being laughed at however it seems likely that the power imbalance between patients and staff members that is common in health care settings may play a role (Baba 2013; Tang and Browne 2008). All patients are likely to feel somewhat disempowered in relation to medical staff however this may intensify when patients are marginalized by factors such as racialization or low socioeconomic status (Tang and Browne 2008). For Aboriginal patients specifically, this power imbalance is colonially rooted and may strongly contribute to patients' fear of speaking up in health care settings.

The CHRs recognized the importance of the communication services they provided. One explained that some patients were quiet and did not ask questions of medical staff, even if they were confused. The CHRs checked in with these patients to ensure there was adequate understanding, and communicated any concerns to medical staff. Another CHR described a patient who went to the emergency department for bloodwork but, “never told them at the front that her heart was bothering her.” (2014b:11). Fortunately the patient mentioned her heart problem to the CHR, who informed admissions to ensure that testing was done. If the CHR had not been present the patient would have left without her heart condition being examined, which could have serious health impacts.

Participants also appreciated simply having an Aboriginal staff member present in the emergency department. Seeing an Aboriginal employee made them feel, “comfortable” and, “welcome” (2014b:11), which is not how they typically felt in health care settings. One participant commented that he, “wasn't looked down [upon]” (2014b:11-12) like he normally was in the emergency department and he attributed this to the presence of the CHR. Participants immediately felt more relaxed upon seeing the Aboriginal CHRs present and did not worry about being judged

or mistreated. The authors suggested that Aboriginal people have a, “sense of solidarity and community” that is very meaningful (2014a:E10), which is why having a CHR to accompany patients in the emergency room may be comforting for patients. One participant commented that, “just seeing someone of your own culture and knowing – [they are] like understanding, not judging.” (2014b:11). Based on the findings shared in Hadjipavlou et al. (2018), this solidarity may in large part be due to the shared historical background of Indigenous people in Canada.

Overall the intervention was a success, with participants speaking highly of the CHRs and having generally better emergency department experiences than they had prior to the intervention. The authors concluded that CHR services in the emergency department were, “essential” (2014b:14), suggesting that interventions like this have significant potential for improving health care experiences for Aboriginal people.

Discussion

The studies discussed in this section provided examples of health programming intended to benefit Indigenous people in different ways. All of the interventions had positive feedback from Indigenous participants, suggesting that similar interventions may be successful in additional health care facilities to those included in the studies.

Auger et al. (2016) stated that their study took place in Vancouver, however the other studies in this section did not reveal the specific geographic location of their study, instead broadly citing Canada (Hadjipavlou et al. (2018) and Tu et al. (2019)) and Western Canada (Cameron et al. 2014a and 2014b). This makes it difficult to determine if these interventions would work in a different area, due to differences in provincial health care systems. Without knowing the geographical area of the other studies, it is difficult to understand the context in which the interventions were successful.

Two interventions discussed focused on traditional Indigenous health practices and one focused on Indigenous peoples' overall experiences in mainstream health care settings. Traditional practices are appreciated by many Indigenous people. However, not all Indigenous patients want these services, and as such it is important to always consider both cultural and non-cultural programming, as was done in this literature review, to ensure that all patients are able to benefit.

Gaps in the Literature

While the studies presented in both sections of this review were of high quality and contributed important findings, some key gaps should be addressed.

The first is a geographical gap. Multiple studies did not state the geographical location and of those that did the majority were conducted in British Columbia. Findings from British Columbia may not be entirely applicable to other provinces, such as Alberta. Each province dictates its own health policy initiatives, meaning that the health care systems and programming in each province will differ. British Columbia is unique in that it has the First Nations Health Authority (FNHA), which is responsible for planning, management, service delivery and funding of programs to improve how health care is provided to First Nations and other Indigenous peoples (FNHA 2019). The FNHA is the only provincial-wide health authority of its kind and works directly with First Nations, as well as provincial and federal health authorities to implement culturally safe health care practices (FNHA 2019). This puts British Columbia in a different, and arguably better, position than other provinces to improve health care for Indigenous people.

The Indigenous Health Program of Alberta Health Services is also dedicated to improving Indigenous peoples' health but does not have the same responsibilities or resources as the FNHA. As a program within Alberta Health Services, the Indigenous Health Program works with different health zones to ensure that Indigenous people have access to adequate health care. A large part of

the Indigenous Health Program is involved in working directly with Indigenous patients and families to provide cultural services, navigate health care services, and advocate within health care settings (AHS 2020a).¹⁴ What this means is that the Indigenous Health Program and Alberta Health Services differ considerably from the FNHA and health care system in British Columbia.

First Nations in British Columbia are also in a different situation than those in Alberta. There are 198 First Nations in British Columbia, representing around a third of all First Nations in Canada (Indigenous and Northern Affairs Canada 2010a). In contrast, there are 45 First Nations in Alberta. The treaty situation also differs in the two provinces. Alberta First Nations are part of the Numbered Treaties, specifically Treaties 6, 7 and 8 (Indigenous and Northern Affairs Canada 2010b). Only small parts of British Columbia have historic treaty agreements, although modern treaties are being negotiated (BC Treaty Commission 2020). Treaties impact how health care is delivered to different First Nations, meaning that First Nations people in Alberta and British Columbia may not have the same health care experiences. Local research needs to be conducted to implement effective programming that is relevant and realistic in the Alberta context.

A second gap is the limited focus on positive experiences and solutions to ensure more positive experiences. The majority of research has elucidated problems within health care settings (Browne et al. 2011; Goodman et al. 2017; Hole et al. 2015). Although some researchers asked participants about positive experiences too, most findings detailed negative experiences. Different research designs are needed to ensure that studies can capture positive and negative elements, which are both important to Indigenous communities (Hole et al. 2015). Research should also go beyond describing experiences to use these descriptions to generate solutions and recommend policy changes (see Jacklin et al. 2017).

¹⁴ Indigenous Health Program employees are involved in policymaking to some extent but the program does not have full independent control over its policy and funding decisions.

Health care systems are complicated and patients are unlikely to understand the inner workings of these systems. It may be useful to include insights of health care workers, as they will have a better idea of what interventions are possible within the system. Speaking with Indigenous health care workers may be particularly useful as these individuals can provide an insider perspective as both Indigenous people and health care workers. Additionally, highlighting that Indigenous people are actively trying to improve their health and health care experiences, instead of focusing only on problems they face, is key to avoiding deficit research (Fogarty et al. 2018a). Deficit discourses are prevalent in Indigenous research in general and Indigenous health research specifically. These discourses portray Indigenous people, “in a narrative of negativity, deficiency and failure.” (Fogarty et al. 2018a:3). Deficit research can perpetuate negative views of Indigenous patients, portraying them as “whining” or “playing the victim” in health care settings (Fogarty et al. 2018a). The irony is that health care systems are designed specifically to deal with illness and medical emergencies – for all patients, Indigenous or not.

Strength-based approaches are increasing in use to counter deficit discourses. One strength-based approach involves highlighting assets that Indigenous people and communities have, with the goal of empowering Indigenous people and in turn improving wellbeing (Fogarty et al. 2018b). One asset that Indigenous people have is a wealth of insight into their health care experiences and what is needed to make things better. Including Indigenous people in the creation of recommendations is one way to combat deficit discourses through a strength-based approach. The inclusion of Indigenous perspectives will help present a more positive view of Indigenous people and create needed improvements in programs and interventions for Indigenous people, which is the primary goal of decolonizing research (Tuhiwai Smith 2012).

The studies in this review that discussed health interventions are excellent examples of studies that focused primarily on sharing positive impacts. However, without knowing the location of these studies it is difficult to determine if similar interventions would be successful elsewhere. Additionally, there are existing programs within Alberta Health Services that have yet to be discussed in detail in any research. The success of these programs should be shared.

The third gap is that despite the many potential benefits of working with Indigenous staff members their perspectives are rarely included in research. Cameron et al. (2014a and 2014b) included comments from Indigenous CHRs, however no other studies in this review included perspectives from Indigenous staff members.¹⁵ To help fill this gap, this current research focuses on Indigenous Hospital Liaisons. The Indigenous Hospital Liaison program is a service provided within Alberta Health Services. Indigenous Hospital Liaisons are dedicated to improving Indigenous patients' experiences in hospitals any way they can, from the emergency department, to admission, until patients are discharged. They are intended to be the first point of contact for Indigenous patients to receive support within hospitals. Although not available at all sites, patients who are able to access this service tend to have highly positive experiences with these workers. Patients confide in these workers about issues they encounter within the hospital and the Indigenous Hospital Liaisons try their best to improve the situation.

Alberta Health Services has stated that Indigenous Hospital Liaisons occupy an important position for improving health care for Indigenous patients (Berg 2018). These workers have rarely been included in Alberta Health Services research, and to my knowledge they have not been included in research outside of Alberta Health Services either. These individuals are considerable assets to Indigenous people in Alberta and to Alberta Health Services overall. My hope for this

¹⁵ There are also few studies outside of this review that include perspectives of Indigenous health care workers. I could not find any studies expressly dedicated to the insights of these individuals.

research is that the inclusion of Indigenous Hospital Liaisons will empower and highlight the strength of Indigenous people in Alberta, in keeping with a strength-based approach. Their considerable insight and experience, as well as their commitment to improving the health of Indigenous people, makes it clear that these individuals will play an integral role in creating recommendations to improve health care, and health, for Indigenous patients. The insights of these individuals are the focus of this research and I discuss the details in the next chapter.

Chapter 3: Research Methodologies

In this chapter I describe the methods used to carry out the current research. I first discuss the theoretical perspectives that informed the study. I then describe the methodology and explain why these methods were chosen. This includes the study design, sample information, data collection and data analysis. The chapter concludes by discussing one limitation of the study.

Theoretical Framework: Decolonizing Research

A decolonizing theoretical framework helped guide my decisions throughout the research process, ensuring that the methods and research goal reflected the principles of decolonizing research. Decolonizing research involves centering Indigenous perspectives and respecting Indigenous knowledge in all aspects of the research process (Kovach 2009; Tuhiwai Smith 2012). It provides a contrast to previous research that has neglected Indigenous perspectives in favour of colonial or dominant-group perspectives. A decolonizing lens should be used for research involving Indigenous people that is carried out by non-Indigenous researchers to ensure that Indigenous perspectives are prominent. Indigenous scholar Margaret Kovach discussed how Indigenous methodologies can be utilized in academic research through the use of tribal knowledges and an incorporation of culture into the methodologies, in her work *Indigenous Methodologies: Characteristics, Conversations, and Contexts* (2009).

While Indigenous methodologies are intended for use by Indigenous researchers, she noted that there are opportunities for non-Indigenous researchers to support these methodologies. She also advocated for use of a decolonizing lens within Indigenous research methodologies, as this lens enables power dynamics between the researcher and participants to be examined and also enables the possibility of transformative research to create positive changes. She suggested three ways of using a decolonizing lens, two of which involve linking decolonizing theory to a specific

tribal methodology.¹⁶ I utilized Margaret Kovach's third strategy: using a decolonizing lens as the central epistemology which aids in its use for transformative designs (2009:80).

This approach is better suited to non-Indigenous researchers who want to respectfully engage Indigenous people in research. It does not involve Indigenous methodologies but rather incorporates a decolonizing lens into Western methodologies. In her work, Margaret Kovach maintained that a decolonizing lens must be incorporated in research with Indigenous people to ensure that Indigenous voices are represented (2009:81). This is echoed by other anti-oppressive scholars, who have emphasized the importance of using a decolonizing lens to place the perspectives and concerns of Indigenous people at the centre (Chilisa 2012).

One of the primary ways that I ensured decolonizing principles were incorporated was by expanding the focus to include both positive and negative aspects of health care within Alberta Health Services. Further, I felt it was important to highlight the dedication of the Indigenous Hospital Liaisons included in this study. This powerful quote from an Indigenous participant at a health conference emphasizes the need for strength-based approaches:

We are tired of researchers coming in and documenting all the things wrong with our communities...How about some research on what's right with us? About what makes us resilient (Ball 2005:86, quoted in Strega and Brown 2015:5).

This quote perfectly encompasses the need to move from deficit-based approaches to strength-based approaches and was instrumental in developing my research design. This quote prompted me to shift my focus from a study that primarily aimed to highlight negative health care experiences, to a study that highlighted the work done by Indigenous Hospital Liaisons and discussed ideas for improving health care.

¹⁶ For example, Indigenous scholars in Alberta may utilize a local Blackfoot methodology. Given my position as a non-Indigenous researcher, it is not my place to engage in tribal methodologies and claim them as my own.

In her influential work *Decolonizing Methodologies: Research and Indigenous Peoples* (2012), Māori scholar Linda Tuhiwai Smith discussed 25 themes to incorporate in Indigenous research such as healing and self-determination. I incorporated the principle of *representing*, which involves countering negative images of Indigenous people that are common in mainstream society. It also involves making recommendations to solve problems that Indigenous people face (2012:152). This current research highlights the valuable work of Indigenous Hospital Liaisons to provide a positive image of Indigenous people. It also includes suggestions for improving Indigenous peoples' experiences within health care. I also incorporated the principle of *envisioning* by highlighting existing beneficial resources and sharing participants' insights on how meaningful the Indigenous Hospital Liaison position is to them and how it can benefit Indigenous patients.

Research Design

This qualitative study utilized a modified multiple case study approach,¹⁷ which involves using data to explore a real-life case or context-specific situation (Creswell 2013). A multiple case study approach seemed well-suited to the study as each Indigenous Hospital Liaison worked in a different Alberta hospital site. Four sites were located in urban areas and one was rural. Sites were selected based on whether they had a full-time Indigenous Hospital Liaison. Further, the Indigenous Hospital Liaisons were self-selecting and had to be willing participants.

Each site constitutes a case, and findings from each site could then be used to illustrate overall themes of Alberta hospitals. In a typical multiple case study individual case descriptions are provided before generalizations are made across cases to illustrate the larger case (Bishop 2012). However, because each participant is connected to a specific site I decided against providing

¹⁷ In a traditional case study multiple sources of data are used to produce the findings. In this study, although multiple "cases" are examined in the form of multiple hospitals, the findings are based entirely on interviews with the participants.

individual case descriptions. Describing the individual sites would make it possible to identify the five sites included and therefore identify the five Indigenous Hospital Liaisons who participated. Participants were promised confidentiality and to ensure this only the larger case of hospitals in Alberta is discussed.¹⁸

Five individual semi-structured interviews with Indigenous Hospital Liaisons were the source of information in this study (see interview protocol in Appendix A). Background information and characteristics of participants can be found in Chapter 4. Insights from an interview with a Traditional Wellness Worker who also participated are included in Appendix D.¹⁹

Determining the Sample and Finding Participants

Although initially I explored the idea of speaking with Indigenous patients about their experiences I ultimately decided against this. Many studies have focused on elucidating patient experiences and had similar findings, as discussed in Chapter 2. These studies detailed common problems that Indigenous people encounter within health care. An understanding of these issues is necessary so that solutions can be found to mitigate them. However, I did not think that another study with patients would necessarily provide many new insights and would not fill the identified gaps in the literature, aside from the geographical gap by focusing on Alberta.

There were also potential logistical issues associated with working with patients. Locating participants could be difficult for an individual researcher like myself, without a research team or community connections to help with recruitment. Following-up with participants could also be challenging. Receiving ethics approval as a graduate student researcher could be complicated by working with patients as these individuals are considered a more vulnerable population and

¹⁸ Therefore, although multiple cases were examined, they were all used to only the larger case of Alberta Health Services hospitals.

¹⁹ This was done to ensure the Research Findings Chapter is clearly organized and easy to follow. The selected insights shared in Appendix D provide support for some of the findings.

therefore additional precautions would need to be taken. Given the typical timeline for a Master's thesis, working with patients seemed unrealistic. Additionally, I wanted to share the findings of this research in a timely manner so that they could potentially be considered for budget restructuring decisions, as Alberta Health Services is currently facing the possibility of funding cuts (Fieldberg 2020). The findings may not actually inform these decisions but making them available makes this a possibility.

However, the main reason I decided against speaking with patients is that I did not feel it was the right type of study for me to do at this stage in my personal decolonizing journey. I felt there were ethical issues involved with speaking to Indigenous patients as a first-time, non-Indigenous researcher. The First Nations Health Authority uses the term cultural humility to describe the process of self-reflection that non-Indigenous people must constantly engage in to ensure they are building trusting, respectful relationships with Indigenous people (FNHA 2020). Cultural humility also involves recognizing ones' self as a learner, rather than an expert, when it comes to understanding the experiences of another person. This requires recognizing and navigating the power imbalances between the researcher and the research participants. After self-reflecting on my own position as a new, non-indigenous researcher, I did not believe I was far enough in my own decolonizing journey to engage in research with Indigenous patients and navigate the associated power dynamics. I also felt that research involving speaking to patients about their personal health care experiences should be Indigenous-led, and therefore this was not the right study for me to engage in.

The decision was made to shift the research focus and work with Indigenous Hospital Liaisons, who are unique employees within Alberta Health Services. This decision was made after consultation with my supervisor and discussions with an Indigenous Health Program

manager who expressed interest in the research. Speaking with Indigenous Hospital Liaisons, who are established Alberta Health Services employees, felt more appropriate for where I am currently at in my decolonizing journey. Further, it would be less personally invasive than speaking with patients who are currently experiencing poor health. Instead of exploring patient experiences first-hand, this current research explores the insights of Indigenous Hospital Liaisons and common issues with which they assist patients in navigating. Working with these individuals aided in the use of a strength-based approach, as I was able to include a description of the work that these individuals do and their suggestions for improving health care for Indigenous people as a prominent portion of this research. Shifting the focus to Indigenous Hospital Liaisons also enabled a greater focus on highlighting existing resources available to Indigenous patients. As Indigenous employees who work directly with patients and staff members, these individuals have a foot in both camps so to speak. The uniqueness of their position enables them to have insight into patient experiences as well as staff actions and attitudes.

Five Indigenous Hospital Liaisons participated in this study. All self-identified as Indigenous and were employed full-time at a hospital in Alberta. One Traditional Wellness Worker, another position within the Indigenous Health Program, was also selected after being recommended by multiple staff members for inclusion in this study. His inclusion reflects the collaborative nature of this research. This participant also self-identified as Indigenous and was employed full-time at the time of his interview. This made for six participants in total.

Data Collection

Individual semi-structured interviews were carried out with each participant. Questions were divided into categories: Personal Information; The Job; Work Environment; and Creating Improvements. Two additional questions (included in Appendix B) were added for the rural

participant which focused on the uniqueness of a rural site. The questionnaire was modified for the Traditional Wellness Worker (included in Appendix C). Each interview lasted between 40 minutes and 2 hours and was digitally recorded, with consent, and transcribed verbatim by me. During the interviews I made notes to complement the transcripts during the data analysis stage.

When creating the interview protocol I ensured opportunities for participants to speak positively and negatively about health care and their position. For example, I asked participants about both challenging and rewarding aspects of their role. Similarly, I asked about both existing resources that are effective and additional resources that may be needed. I did not want to bias the findings by taking an interest only in positive or negative aspects of health care. This interview approach enabled me to gain insight into aspects of health care that participants identified as problematic for Indigenous patients, while also highlighting beneficial resources and ensuring that there was a prominent focus on creating improvements.

Data Analysis

Qualitative content analysis was carried out on the interview transcripts using a combination of hand-coding and NVivo12 coding software. This is generally viewed as the analysis technique best suited to descriptive or exploratory qualitative studies (Mayan 2016). It involves analyzing qualitative data, typically in the form of textual passages, to identify and sort the patterns that emerge from the data. This type of analysis enables the researcher to include the intent of participants within the coding process (Mayan 2016).

I went through each transcript by hand multiple times, each time adding additional codes. I then went through the transcripts in NVivo. Hand-coding was useful for me as I found NVivo to be overwhelming at first and was initially grouping large sections of text into a single code. Data analysis was an ongoing, iterative process, as is common in qualitative research (Creswell 2013;

Mayan 2016). Although formal data analysis did not begin until I had conducted all of the interviews, I transcribed each interview within a few days of it taking place and highlighted recurring themes and quotes that stood out to me. Analyzing data, at least partially, throughout the data collection stage is a useful strategy in qualitative data analysis because new areas of inquiry can develop as data collection proceeds (Creswell 2013; Curry et al. 2009). This is in keeping with the inductive nature of this research. As it turned out, I identified some ideas in earlier interviews that I was able to introduce into later interviews.

A constant comparison method of analysis was used. Instead of using line-by-line coding techniques, the transcripts were read more slowly and repeatedly, with each reading drawing out new themes and adding additional codes (Mayan 2016; Oster et al. 2014; Taylor, Bogdan and DeVault 2001.) Coded sections were then analyzed to determine additional commonalities and differences. For example, certain ideas were mentioned by all participants while others were unique to a specific participant and their associated care site (Oster et al. 2014). I then grouped the coded sections according to which of the four research questions they were most relevant to.²⁰ Several coded sections were relevant to more than one research question.

Limitations

I would like to address one limitation of this study, and that is the small sample size. There are six participants in total, including five Indigenous Hospital Liaisons and one Traditional Wellness Worker. Because of the small sample, not all areas of Alberta are represented. For example, only one rural site was included while the four other sites were urban. Fortunately, this limitation is partially mediated by the fact that all hospitals in Alberta are under Alberta Health Services management, so it is likely that there is some overlap between sites. Additionally, as the

²⁰ The four research questions can be found in the Introduction chapter (see P.16).

focus of qualitative case studies is on the richness of detail provided rather than the number of participants, five cases is not considered unusually small (Creswell 2013).

With that said, I could have tried to recruit more participants. I first spoke with an Indigenous Health Program manager about the possibility of this research in April 2019. She shared the idea to a group of Indigenous Hospital Liaisons in June 2019 and five individuals indicated that they were interested in participating. The idea was then discussed more formally in September 2019 and the same five individuals and one additional individual confirmed their participation. The project received approval from the University of Calgary's Conjoint Faculties Research Ethics Board in October 2019, however receiving additional approval from Alberta Health Services took several months more. The result is that the participants who had expressed interest in June had now been waiting many months without being interviewed.

The relationship between Indigenous and non-Indigenous people in Canada has been problematic to say the least. This is true generally as well as specifically in reference to relationships between Indigenous people and non-Indigenous researchers (Kovach 2009; Tuhiwai Smith 2012). In order to move towards reconciliation, relationships need to be strengthened. The Truth and Reconciliation Commissions' final report stated that, "reconciliation is about establishing and maintaining a mutually respectful relationship between Aboriginal and non-Aboriginal peoples in this country," (TRC 2015:6). With this in mind, I wanted to make sure that I was respecting the participants in this study by completing the research and sharing the findings with them within a few months of their interviews.

The participants showed respect to me in multiple ways, from their patience as I awaited ethics approval, to their encouragement when I was nervous during the interviews. To reciprocate and respect the participants I wanted to provide them with written results in an efficient manner,

which is why I decided to finish this research with the original participants instead of delaying the project to try and recruit more participants. I believe that future research should include more Indigenous Hospital Liaisons from other sites in Alberta, as the insights that I heard from participants in this study demonstrated how committed these individuals are to improving health care for Indigenous people in Alberta.

Chapter 4: Research Findings

The findings shared here are based on individual interviews I conducted with five Indigenous Hospital Liaisons.²¹ I use the findings to address each of the four research questions introduced in Chapter 1. I begin with the first question: What is the role of Indigenous Hospital Liaisons in hospitals within Alberta Health Services? To answer this question I discuss the findings as they relate to two areas: the uniqueness of the Indigenous Hospital Liaison role within Alberta Health Services; and the common services that Indigenous Hospital Liaisons provide. First, however, I provide a discussion of some of the personal characteristics of participants in this study.

Characteristics of Indigenous Hospital Liaisons

Each interview participant was asked to discuss basic characteristics about themselves, including the length of time they had been in the liaison position, their previous field of employment, whether or not they were from Alberta, and other characteristics.

As seen in Table 1 (below), four participants self-identified as First Nations and one identified as First Nations and Métis. Four participants were Status and one identified as a non-Status First Nations person. Of the Status participants, two were from Alberta while two were originally from other provinces. The non-Status participant was also from another province.

The Indigenous Hospital Liaison program has been in existence for more than 20 years, albeit in slightly different forms and with different titles. Participants had been in their position as full-time Indigenous Hospital Liaisons for various lengths of time, ranging from less than one year to more than 10 years. The majority of the participants had been in the position for more than five years. Prior to their current position, three participants had been employed in social work, one was a former primary care worker, and one had worked in both primary health care and social work.

²¹ Additional insights from the Traditional Wellness Worker who participated can be found in Appendix D.

Participants did not believe the position had specific background requirements, although one thought that her job posting had stated that a background in social work, nursing, or psychology was preferred.

Table 1: Study Participants by Personal Characteristics, 2020

	Participants (N=5)					Total	Cumulative Total
	1	2	3	4	5		
Time in Position							
<1 year					X	1	1
1-5 years				X		1	2
6-10 years		X				1	3
11+ years	X		X			2	5/5
Employment Background							
Social Work		X	X	X	X	4	4
Primary Health Care	X				X	2	5/5
Location of Employment Site							
Urban	X	X	X	X		4	4
Rural					X	1	5/5
Indigenous Affiliation							
First Nations		X	X	X	X	4	4
Non-Status First Nations	X					1	5
Métis		X				1	5/5
Home Community							
Local (Alberta)				X	X	2	2
Outside Alberta	X	X	X			3	5/5
Gender							
Female	X	X		X		3	3
Male			X		X	2	5/5

Source: Link, Indigenous Hospital Liaison Study, 2020

*Note: One participant had a background in both social work and primary health care provision. One participant identified as both First Nations and Métis.

Unique Aspects of the Indigenous Hospital Liaison Role

The Indigenous Hospital Liaison (IHL) role is unique in Alberta Health Services in many ways. The smudging services they provide to patients are one aspect of this uniqueness, and participants themselves identified this. This service is discussed in detail later in this chapter. Here, I explore how participants regularly engage in work that goes beyond the hospital, demonstrating the holistic element of their role. A holistic focus is not typical in mainstream health care systems.

The holistic element of the IHL role ensures that Indigenous patients are taken care of even after they are discharged from the hospital.

The participants in this study are truly committed to Indigenous patients. One participant exemplified this when describing the role of an IHL. He ended his description by concluding:

Basically, making sure as best as possible that they have a safe discharge and a safe place to go, and that they have access to all the resources that are needed for them to have, you know, to live a good life (Participant 3, 17/01/2020).

There is a difference between wanting a patient to have a good experience in the hospital and wanting a patient to live a good life. The latter highlights a commitment to patients that goes beyond the hospital and therefore beyond the official role of an IHL. With employees like this who are so dedicated to helping Indigenous people I feel encouraged that, over time, Alberta Health Services may shift towards a more holistic model of care that will benefit Indigenous patients, not just within hospitals, but in other aspects of their life.

This holistic focus is quite unique to the IHL role within Alberta Health Services. Holistic care, according to participants, involves considering all of a patients' needs, beyond just their medical needs. The participants' focus on holistic care is evident and emphasizes their commitment to their patients. This often involves them considering factors that are not directly related to a patients' hospital experience. As one participant shared:

There's a lot of things that we check with the patient about, you know, what's happening with their life and what's going on before, you know, and if they're willing to tell what you know may have happened to them in the past so then how they ended up here in the first place, all of that is relevant (Participant 3, 17/01/2020).

This highlights how IHLs assess a patient's situation by considering their life as a whole, instead of focusing only on aspects that have a direct link to the patient's health. Another participant explained:

We're more about holistic healing and not just focused on the medical part of it. So making sure, you know, what if they don't have food when they leave the hospital, we can let them know the resources to access it, things like that, right, like they're not just a broken arm to us (Participant 4, 24/01/2020).

The comment that patients are, “not just a broken arm” again emphasizes a difference between primary health care providers and IHLs: the former focuses almost entirely on physical aspects of health while IHLs consider all the needs of a patient. This is not to say that health care providers are doing something wrong by focusing on the medical aspect but to suggest that positions such as IHLs are necessary to make sure that patients’ other needs are also met.

Participants explained that they always try to ensure that patients’ basic needs are met, both inside and outside of the hospital. Participants always ask patients about their food, housing, and clothing situation. Several participants mentioned trying to make arrangements with their hospital’s food services staff to provide meal vouchers for Indigenous families who come from out of town or who cannot afford meals. One participant noted that vouchers at his site are limited, due to apparent budget cuts to the Indigenous Health Program in recent years. If he is unable to obtain vouchers, he will sometimes pay for a family’s meals out of his own pocket. He does not feel obligated to do this but chooses to because he likes being able to, “[make] their stay easier” any way he can (Participant 3, 17/01/2020). This participant goes above and beyond the role of an IHL, or any position for that matter, simply because he is committed to making Indigenous patients and their families as comfortable as possible.

To ensure that patients’ other basic needs are met, participants refer patients to on-site clothing banks, when available, if patients do not have extra clothes with them and do not have friends or family members who can bring them any. This can be especially useful for homeless patients who are less likely to have additional items with them when they visit the hospital.

Participants also discussed working with homeless patients specifically to try and improve their housing situation whenever possible, or at least ensure they have a place in a shelter.

What Services do Indigenous Hospital Liaisons Provide?

Participants walked me through their daily routine and discussed common services that they provide to patients, family members, and staff. I focus first on communication services, which are the most common services that participants described. Two types of communication services are discussed, Translation and Patient Advocacy. I then discuss two additional services, Smudging and Non-Indigenous Forms of Spirituality. Participants also frequently discussed helping patients navigate the Non-Insured Health Benefits (NIHB) program; this is another major service that they provide. However, this was primarily discussed in the context of issues with NIHB and as such this service is discussed later in the Barriers section of this chapter.

Bridging the Gap: Enhancing Communication

IHLs provide many kinds of communication services by regularly speaking with patients, staff, NIHB coordinators, CHRs, and community organizations, all to ensure that the patients' needs are met. This section focuses on how participants aid in communication between Indigenous people (including patients and family members) and health care staff, which was by far the most commonly discussed type of communication. All participants made reference to the importance of, "bridging the gap" or, "bridging understanding" between Indigenous people and members of the medical team.

Translation

Participants frequently explain medical jargon and procedures in clearer terms to Indigenous patients. They discussed how Indigenous patients, like most patients, do not always understand the medical terminology used by health care workers. This terminology is very familiar

to health care staff and because of this they may not take the time to explain these terms, even though all patients would benefit from an explanation. As one participant explained:

I mean our people, and I'm hesitant to say "our people", because most of us don't know all this medical stuff jargon, I mean there's a lot of stuff I don't know what the heck you're talking about. So it's explaining it as best as possible in the simplest terms that a family or the patient will understand what's going on, in the way of their care and things like that, so again it's the communication part of it, it's having the ability to be able to communicate with the people (Participant 3, 17/01/2020).

IHLs were often asked to be present at family meetings, which include the patient, their family, and the doctor or other members of the medical team. Patients and families often feel more comfortable having an Indigenous staff member present. The medical team may also request the IHL's attendance to ensure that all necessary information is clearly communicated to and understood by the patient and family. The IHL role in these meetings is supportive and they step in throughout the meeting to ask if either party has questions. One participant explained:

Um, help [the doctor] if they're explaining things, help them just take it slow. And allow the family members to ask questions and making sure that they understand what's going on, what's happening to their family member, you know...Just to help, helping out with the understanding and then asking the family if they've heard everything, have they been able to understand everything, and if they're not then maybe having the doctor explain again. And so making sure that there's a good understanding between the two parties that are involved (Participant 3, 17/01/2020).

IHLs aid in communication for both parties. They want to ensure that patients and their family members understand the medical information and that the doctor has all the information they need from the patient.

Another participant discussed providing literal translation services for patients who are more comfortable speaking an Indigenous language. He commented:

They feel more comfortable and they understand it more clearly when I translate it into my own language...So I do translation, especially for elders that sometimes have a hard time translating, uh, their needs in English (Participant 5, 29/01/2020).

This participant works at the rural site in this study and many patients are from a nearby First Nation. Many patients speak the same Indigenous language and can therefore easily communicate with Participant 5, who is from the local area. At an urban site, there are likely to be a wide variety of Indigenous languages spoken, making translation services difficult to provide. None of the urban participants discussed providing literal translation services.

Patient Advocacy

Previous studies have suggested that Indigenous patients are often reluctant to voice their concerns to staff members (see Cameron et al. 2014b). Participants echoed this, explaining that they often act as a voice for Indigenous patients who do not speak up to staff members:

The link between patients and the Indigenous liaison, we're there as a spokesperson, I guess, for the patient. If they have any concerns with their care, then we're there to speak on their behalf. We can address their concerns and address that to the doctors and nurses, or even to their own family. Um, so we're there as a voice. And we are kind of filling the gap between the patients and the doctors (Participant 5, 29/01/2020).

IHLs help to ensure that patients' questions, needs and concerns are clearly expressed to the medical team. Another participant explained:

Sometimes it's because they don't think they're being heard, or their uh voice doesn't matter, they'll say "Well I try to tell [staff members] but they don't listen. So then I will have a conversation sometimes with the nurse, to see if there's anything happening (Participant 3, 17/01/2020).

These comments highlight the importance of IHLs in helping patients gain clarification from staff members about their medical concerns when they feel they cannot ask for themselves. According to participants, patients feeling they were, "not being heard" is a common problem they are asked to help with. Participants were unsure why patients felt this way, although it was suggested that a general discomfort within hospitals was one cause. This is discussed further in the Barriers section of this chapter. Based on existing literature and the insights of participants, it is

reasonable to suggest that previous mistreatment within health care settings is another reason for this reluctance to speak up (see Browne et al. 2011, Goodman et al. 2017, and Hole et al. 2015).

Staff members may also request an IHL if they worry that patients are not opening up to them. The liaison can speak privately with patients and then inform the medical team of relevant information or any concerns of the patient. Participants noted that they frequently receive referrals of this type. One participant explained:

Staff will ask for me, uh, usually to see how the patient is really feeling, because patients do not open up to nurses all the time, and uh some of them will hide their pain, um, or their emotions. And they usually just tell me you know can you just kind of sit down and talk to them to see what's really bothering them, exactly what kind of pain they're having because, you know, they're not always forthcoming with that to the nurses here, or the doctors. So that's one of the things they ask me is to sit down and you know chat with [the patient], cause they say that they might be more trusting with me, and open up more with me. And they do (Participant 5, 29/01/2020)

Although patients may be unwilling to share their feelings and concerns with the medical team, this information is necessary for the medical team to provide care tailored to the patient's needs. Another participant shared an example from her experience:

I had this um this family who um, they were going through a really tough time and they would only speak to me. And uh they would only speak to me and the medical team was having problems, so basically I had to sit in on all the meetings, just to show that like we were there supporting them, and you know there to help if they needed it, um, but inevitably it's the medical team and things like that that are helping work out the care plan in the best interest of the patient. So it's um liaising, it's kind of mediating between that, right? (Participant 4, 24/01/2020).

Participants were clear that they only disclose relevant information to the medical team in order to protect the privacy of the patients. The information they share with the medical teams can be essential in developing an adequate care plan for the patient. This reinforces how IHLs benefit both staff and patients, as staff can gain additional information to best develop a care plan that results in high quality care for the patient.

Smudging

Participants frequently discussed that a major part of their job involves helping patients connect to Indigenous culture and engage in prayer and ceremony. This may mean providing cultural services themselves or referring patients to additional resources. Multiple participants spoke about requesting Traditional Wellness Workers or Elders to visit patients at end-of-life to facilitate ceremonies for families. However, this section focuses on the most common service that participants personally provide to patients, smudging.

The weekly smudging ceremony hosted at many Alberta hospitals is one way that Indigenous patients can connect to Indigenous culture and engage in prayer and ceremony.²² It is typically facilitated by an Elder or Traditional Wellness Worker. One participant explained that at his site he personally facilitates this weekly ceremony. Another participant facilitates the ceremony only if the regular facilitator is unable to attend. At most sites the smudging ceremony takes place in a specific location that has adequate ventilation and does not require smoke detectors or other maintenance services to be shut off.²³

Unfortunately, not all patients are able to attend the weekly smudging ceremony, for a variety of reasons. Patients may have mobility issues that prevent them from attending, restrictions from the medical team, or time conflicts. However, there are other ways that patients can access smudging. Participants spoke about bringing patients to the ceremony space outside of the regular ceremony time to enable them to smudge:

Most of the time if [patients] want to smudge they're able to come down with me to the [ceremony space] here in the hospital and we can do that here in the hospital.....Any time, I take care of any time uh other than the regular smudging

²² As mentioned in the Introduction chapter, many sites within Alberta Health Services have a traditional Indigenous smudging ceremony once per week at a designated time (see P.14-15).

²³ Smudging ceremonies involve smoke, so the ceremony site must be properly ventilated and/or have outdoor access to clear the smoke following the ceremony.

ceremony. I take care of the rest of the week, if any patient wants or is wanting to smudge (Participant 3, 17/01/2020).

Patients can also sometimes smudge in their hospital rooms, if they have a private room and if there is enough time in advance to ask maintenance services to shut down the smoke detectors. Another participant shared her experiences and commented on the positive impact that personal smudging services can have for patients:

I light smudges for people so they can pray, I had this uh person recently who, um, felt really isolated and stuck because they couldn't leave the unit or anything like that, so bringing prayer to them, and he said that out of all the talking he was doing, that was the most healing part of it was being able to pray and connecting with, reconnecting with uh the Creator, and everything (Participant 4, 24/01/2020).

Participants agreed that for many patients, smudging seems to have a significant positive impact on their overall hospital experience.²⁴ One participant discussed her role in setting up additional smudging times for patients at her site, to provide greater access to patients:

I spoke to the chaplains and spiritual care, so we've always had the smudging ceremony at the same time. Who's to say we have to have it at this time? How about we open it up on other days, when there's availability, so now they do. So on [additional days and times] they announce that, and it's posted [at the space]. Without my involvement! So say somebody's feeling sad and they need an extra smudge, they can just go in there cause it's open. Who are we in Alberta Health Services to say you can only go in at this time? (Participant 1, 10/01/2020)

This participant demonstrated initiative and advocated to benefit Indigenous patients. This created a significant change and demonstrates the dedication that IHLs have to making Indigenous patients more comfortable while in-hospital.

Non-Indigenous Forms of Spirituality

Spirituality is an important part of the healing process for many Indigenous patients, however this is largely unrecognized in mainstream health care (see Auger et al. 2016 and

²⁴ I have seen this myself as a volunteer, with some patients eagerly waiting for me to pick them up for the smudge each week.

Hadjipavlou et al. 2018). Participants recognize the importance of meeting patients' spiritual needs and do whatever they can to provide services. Smudging is also a spiritual service, however because participants discussed smudging in detail I wanted to include it as its own discussion.

Not all Indigenous people follow traditional Indigenous culture or practice Indigenous forms of spirituality. Participant 2 explained that many Indigenous people hold Western denominational beliefs such as Roman Catholic or Anglican beliefs; other participants agreed that Christianity generally is a prominent belief system among many Indigenous patients. Further, some Indigenous people who practice traditional spirituality also hold other religious beliefs. The spiritual needs of these individuals may not be fully met through traditional practices alone.²⁵ According to participants, these individuals greatly benefit from access to both traditional and non-traditional spiritual resources. Participants discussed their willingness to provide non-traditional²⁶ spiritual services and resources to patients whenever possible. Participant 1 shared this example:

A good example is I was given holy water from a Northern community years ago...And that day has come where there are individuals who won't follow the traditional way of life but they uh do follow the Catholic tradition, and they say "I would really like some holy water", I have that to give it to them. That is so meaningful (Participant 1, 10/01/2020).

Although this patient did not practice Indigenous spirituality, Participant 1 was happy to assist them in meeting their other spiritual needs. Another participant discussed how she has worked to build strong relationships with the chaplains²⁷ employed at her site to ensure that the spiritual needs of patients who practice both traditional and non-traditional spirituality are met:

²⁵ In my experience as a volunteer, I have met many patients who pray to both Creator and God during the smudge, for example.

²⁶ In this context, non-traditional refers to non-Indigenous forms of spirituality and prayer. For example, some Indigenous patients may wish to engage in Catholic practices.

²⁷ According to participants, Spiritual Care Services at most sites are equipped to assist patients with Roman Catholic, Islamic, and traditional Indigenous beliefs, although the chaplains will meet with any patients who request their services, no matter what religion the patient is. Additionally, patients and families can request services from religious leaders outside Alberta Health Services, who will collaborate with Spiritual Care Services.

I work with the chaplains, I have a really good relationship with the chaplains. If I'm asked by a family to pray, I honour their wishes and do it, but I can ask the spiritual care that's part of that unit to be part of that. And it really goes very well because I do my role in the traditional part to the best of my ability, and then the spiritual care, they can do their prayer too. It has been really good for the families here (Participant 2, 13/01/2020).

Participants spoke fondly of their relationships with Spiritual Care Services at their sites. Strong relationships between the IHL and chaplains at a site can help ensure that patients' spiritual needs are fully met, no matter what this entails.

Summary

The findings in this section have answered my first research question. I briefly discussed the background characteristics of participants before discussing unique aspects of their role, and then describing common services that they provide. IHLs work to make sure all the needs of a patient are attended to, including basic needs, communication needs, and cultural and spiritual needs. These findings provided considerable detail into the role of IHLs. The next section explores barriers in the health care system and addresses the second research question.

Barriers in the Health Care System

This section explores barriers that participants felt were commonly encountered by Indigenous people when accessing health care.²⁸ Participants identified these barriers based on their experience working with Indigenous patients in hospitals. Helping patients navigate and overcome these barriers is part of the IHL role. The findings presented in this section address the second research question: What do Indigenous Hospital Liaisons identify as common barriers that Indigenous patients encounter when accessing health care in Alberta? The barriers are categorized into two major areas: Access Barriers and Discrimination. Each is further broken down to illustrate

²⁸ The participants identified multiple barriers, however I only include those that were mentioned by all or almost all participants, to ensure that the focus is on barriers that are applicable across multiple sites in Alberta.

multiple types of barriers within these larger categories. An additional barrier, Hours of Service, is a challenge related to the IHL role and is also included in this section. Access Barriers are discussed first.

Access Barriers

The barriers included under this grouping make accessing health care and health care-related services more challenging for Indigenous patients. These barriers are often due to organizational or structural issues. Three barriers of this type are discussed in order: Transportation; Issues with the NIHB Program; and Limited Access to Family Doctors.

Transportation

Transportation to and from health care facilities is a challenge for many Indigenous people. The hospitals in this study do not provide transportation assistance to the site, aside from emergency ambulatory services.²⁹ Patients are therefore responsible for finding their own means of getting to the hospital. Depending on the circumstances and the specific site, transportation may be provided for patients upon being discharged if patients are unable to arrange their own transportation. This may be in the form of taxi fare, however participants noted that it was commonly only a ticket for public transportation. For patients with mobility issues, both options may be insufficient.

Indigenous patients living on-reserve may qualify for medical transportation that is covered by Non-Insured Health Benefits (NIHB), however there can be issues with this as well. One participant noted that on-reserve health centres are responsible for providing NIHB medical transportation however these centres, due to limited staff and resources, “can only provide so much, and they have a policy as to who they can transport.” (Participant 5, 29/01/2020). This

²⁹ There may be exceptional circumstances where patients and families can be reimbursed for transportation costs; however the general consensus from participants was that transportation to the hospital is not provided.

means that not all on-reserve patients can access this transportation when they need it. Participant 5 explained that in order to qualify for medical transportation to a reserve following a hospital visit, patients need to be brought to the hospital by ambulance. If patients find another way of getting to the hospital, such as being driven by a friend, they will not qualify for transportation back home. The reasoning is that they will have demonstrated their ability to arrange their own transportation. This can be especially problematic in rural areas, where many people, “do not have vehicles at all” (Participant 5, 29/01/2020) and arranging a ride may be difficult and unreliable.

Health centres are only able to facilitate medical transportation during certain hours, typically standard hours of 9am to 5pm. Alternative transportation has to be arranged if patients are discharged outside of these hours. A participant explained that the main Alberta NIHB office can be contacted after-hours or on weekends to arrange alternative means of transportation, however this needs to be done by hospital staff other than IHLs, who only work standard hours on weekdays. This participant was confident that most of the nurses at his site knew about this process however the frequent staff turnover at most hospitals means there may be instances where staff members are unaware of NIHB processes. Additionally, Participant 5, who shared these comments, is employed at a rural hospital, which is also the smallest site in this study. While most nurses at this site may be aware of NIHB procedures, in a larger site it is more likely that there will be staff who are uninformed about these procedures.

Another participant shared a transportation problem that can potentially put patients in an unsafe situation. Transportation provided by the hospital can only take patients home or, in the event of patients without a regular address, they typically drop them off in a central area so they can seek shelter and other forms of assistance. Similarly, medical transportation is typically only for transport to reserves, as it is operated by on-reserve health centres. Patients needing to reach

destinations other than their home address are often unable to do so. Participant 3 shared this example:

The big problem is if a lady comes in and she's being, you know, there's domestic abuse, most of the time she can't get into the [urban] shelters because they're full. But sometimes she can go to the one on [nearby reserve] or in [nearby town]. But the problem is there's no transportation to get her there. She has to find her own way there. And most of the time they can't do that...So often they just end up going back in the same situation (Participant 3, 17/01/2020)

This participant noted that while this situation is not common, it does happen and can put the patient in a difficult and dangerous situation. Having additional transportation options available for patients in unique circumstances could be a significant benefit, however at the time of writing it does not seem that this is an option at most sites.

It is important to recognize that although NIIHB medical transportation was commonly discussed in relation to transportation barriers, this is only applicable to patients with NIHB coverage, specifically patients who are First Nations Status or Inuit. Non-Status and Métis peoples do not receive any additional transportation assistance beyond a possible public transit ticket or taxi fare, the same options available to all Alberta patients. While this means that non-Status and Métis peoples do not encounter the NIHB-related frustrations that many Status patients do, they also have less transportation options. One participant commented that the NIHB system needs to be improved so that Métis and non-Status individuals are also able to access benefits; these changes should be happening in the coming years as a result of the Daniels' Decision (SCC 2016; Vowel 2016), however as of now it is difficult to say what will happen.

Issues with the NIHB Program

Participants explained that helping patients with issues related to NIHB is one of the most common services they provide. As previous studies have noted, the NIHB program undergoes frequent changes, however these changes are not always communicated to patients or health care

providers (Lorde & Small Legs 2010). This leads to situations where patients suddenly appear to not have coverage, or where they must pay out of pocket for a service that was previously covered.

Applying for Status in order to qualify for NIHB is the first hurdle that Indigenous people must overcome to access the benefits. One participant explained that this is a problem that families with children often have to deal with because children are not automatically registered:

There's times where [parents] didn't understand the process uh with NIHB, so of course somebody got turned down because of either their registration, uh, and this is talking about little kids with NIHB, the kids have to be registered before the age of 12 months, one at a time. Now they've raised it to 18 months because with the Gender Equity, there's so many people that are backlogged for getting registered. But still, they have to register very young (Participant 2, 13/01/2020).

The “Gender Equity” referred to here is Bill C-31 which, as previously discussed, enabled many more Indigenous people to apply for Status. This has resulted in a backlog of applications needing to be processed. In addition to long wait times, parents may also encounter problems if they did not register their child at a young enough age. Participant 2 explained that parents often misunderstand and think that if their child is under two years old they do not need to register them separately, believing that their child will be covered under the parents’ own Status benefits. This is not the case, however, and specific procedures must be followed in order to register children. Participant 2 described the entire NIHB registration process as a “rigmarole” and acknowledged that it is frustrating for parents and individual patients to navigate. Participants try to help any way they can by explaining the process in clear terms and contacting the patient’s reserve if there are problems. If issues persist, participants will contact NIHB directly and try to work things out.

According to participants, patients also regularly encounter problems when trying to access services that should be covered by NIHB. One participant explained that although dental services are covered, “there are only some dentists that work through Indian Affairs, so you have to kind of check around to see who is working with Indian Affairs.” (Participant 3, 17/01/2020). He tries

to provide patients with a list of all the dentists whose services can be covered through NIHB, to ensure that patients do not receive services and then find out they are not covered. Similarly, only certain psychologists are covered by NIHB. However, participants agreed that issues related to NIHB coverage for prescription medications are by far the most common.

Participants explained that many patients encounter issues in pharmacies when they are told that their medications are not covered or that they are required to pay out of pocket and then apply for reimbursement. This creates challenges if patients are unable to cover the costs and may prevent patients from obtaining needed medications, which can have negative health impacts. One participant explained that she often gets referrals from medical staff to speak to patients who are not taking their medications:

So people are not picking up their pills, like their prescriptions, and then I find out that it's because um it's a drug that when they first ring it up it shows up rejected. Well it's up to the pharmacist to call the Drug Exception Centre and see what can be done (Participant 2, 13/01/2020).

The participant explained that pharmacists should know to call the Drug Exception Centre but that many do not. She continued:

So I tell patients that if the pharmacist says the NIHB won't pay for it, tell them to call the Drug Exception Centre. Or they can call the prescribing doctor and have them prescribe an alternative that NIHB will cover. I tell them don't ever, ever leave without the medication. But it can be difficult getting things covered or understanding what to do (Participant 2, 13/01/2020).

Part of the problem is that pharmacists may not be fully aware of NIHB processes and therefore may not know to call the Drug Exception Centre. The pharmacist is not necessarily at fault, as NIHB procedures are often poorly communicated to health care providers (Lorde and Small Legs 2010). However, this places the responsibility on patients to know these processes so that they can tell the pharmacist what needs to be done. It is unfair and unreasonable to expect patients to understand NIHB processes that even health care providers do not understand, but

participants do their best to fully explain these processes to patients so that issues can be avoided. Unfortunately, even if proper procedures are followed, there are still situations where a medication simply cannot be covered by NIHB.

Another participant explained that the actual process of submitting a claim after a patient paid out of pocket can be an obstacle. This process used to be mail-in but has now shifted to an online submission system. Participant 5 discussed this in detail, noting that this is particularly an issue in rural areas where technological literacy is generally less common:

Some [patients] have to pay for their own medication. And then for them to be reimbursed, they have to go online and fill out an application and then send it to NIHB. And some are reluctant to do that because they don't know how to operate a computer! That's one of the obstacles I hear a lot is the computer access, to get reimbursed for medications that they're paying for themselves (Participant 5, 29/01/2020).

This is often especially challenging for elderly patients, who generally have lower levels of technological literacy, and patients who are not from the local area and do not have friends or family members to assist them. This participant went so far as to pinpoint NIHB issues as one of the most significant barriers that Indigenous people in Alberta face when accessing health care. Although he helps patients submit their claims online whenever he can, he noted that because he is the only IHL at his site he is not always able to help patients with this in a timely manner. There is only one IHL (at most) at each site and they are often pulled in many directions at once by patients and staff members. Multiple participants commented that they often have more referrals than they can get to in a day or even a few days. If the NIHB process was simpler it could decrease the total number of referrals that IHLs get, enabling them to respond to referrals more quickly.

Limited Access to Family Doctors

Previous studies have acknowledged the lack of available family doctors for Indigenous patients. McConkey (2017) discussed how Indigenous people often find it challenging to find a

family doctor due to their likelihood of having multiple health conditions simultaneously (see Pirisi 2015 for more information on this issue). Many Indigenous people experience multiple health issues, known as comorbidities (Pirisi 2015), and physicians may be reluctant to take on patients with these complex health needs, with some physicians admitting this themselves (McConkey 2017). The reluctance of doctors to take on patients with multiple health concerns combines with a shortage of doctors in general,³⁰ with the result that many Indigenous people do not have a family doctor and are unable to obtain one. With possible funding cuts coming to Alberta Health Services in the near future (see Fieldberg 2020), the problem of a doctor shortage may be exacerbated.

Participants noted that it is harmful to patients' health to not have a family doctor because patients cannot regularly follow-up to monitor ongoing health issues. Participant 1 explained that not having a family doctor prevents patients from having the necessary information to take care of their health. Patients may not recognize the importance of seemingly basic health behaviours, such as regularly taking prescribed medications. She shared an example of a patient who did not take her blood pressure medication and as a result suffered severe health problems:

The unfortunate thing is that she did not know she could prevent what happened to her by taking care of herself. For years she hadn't been taking her blood pressure pills. And so as a result of that, she ended up getting very sick, and it was very sad and she was very young, like, yeah, early forties. So it's unfortunate when I see things like this, because they are not following up, no family doctor, not following up...I see this a lot (Participant 1, 10/01/2020).

The patient in this example had no family doctor or other access to follow-up care. This participant commented that one of the things she tries to do is, “reinforce the importance of taking medication if [patients] have high blood pressure.” (Participant 1, 10/01/2020). In this way, IHLs may be partially filling the gap for patients who do not have a family doctor by communicating essential health information.

³⁰ Participants stated that there is currently a shortage of family doctors in Alberta.

A lack of family doctors may be an even bigger issue in rural areas, due to fewer practices in the area as well as more limited transportation options. Participant 5, from the rural site in this study, confirmed this, explaining that a lack of family doctors is a significant health barrier for many Indigenous people in rural areas, including individuals living on rural reserves. In his area many doctors are not accepting new patients. “Half the community does not have a regular family doctor, of people that come [to his site].” (Participant 5, 29/01/2020). Many people must visit the emergency department to receive basic care. Previous research has suggested that Indigenous people use emergency departments at greater rates than the general population (Dell et al. 2015) and a lack of family doctors may be one reason for this. Participant 5 agreed that many people in his community rely on the emergency department to replace services normally provided by a family doctor, but felt this was not an effective solution:

When they go to Emergency [patients] are told to go see their regular doctor, but they don't have a regular doctor. So who do they go to? And so they have to go to a walk-in clinic to see a doctor. But even there they tell them to go see their regular doctor, because the walk-in is just the temporary doctor right? So I see walk-in clinics as a band-aid solution, temporary (Participant 5, 29/01/2020).

This shows how a lack of family doctors can lead to a cycle of frustration, with patients unable to access basic health care when they need it. Relying on emergency departments is not ideal, as wait times are often long and doctors may not be able to spend much time with each patient. Additionally, studies discussed in Chapter 2 specifically highlighted that emergency departments are often the site of mistreatment, which further suggests that relying on these departments is not beneficial for Indigenous people (Browne et al. 2011). Alberta Health Services also recognized problems with emergency departments in a recent report (Berg 2018).

Participant 5 believed the lack of doctors was more so the result of a rural location and a shortage of doctors in the province generally, rather than a problem of doctors discriminating

against Indigenous patients. He added that, “especially right now with the provincial government doing cutbacks in Alberta’s health care, that is going to have a big impact. So we need more rural doctors.” (Participant 5, 29/01/2020). It is encouraging that he does not think that rural doctors are deliberately not accepting Indigenous patients,³¹ however Indigenous patients do face discrimination in other health care settings, as multiple studies have documented (Goodman et al. 2017; Hole et al. 2015; Jacklin et al. 2017).

Hours of Service

This is not one of the barriers to health care that participants identified, but rather a challenge associated with the IHL role and their ability to help patients navigate other barriers. IHLs typically work a regular workday from 8am to 4pm on weekdays, as was mentioned in the discussion on transportation. There is no overnight or on-call liaison. Because of this, patients who require assistance after 4pm or on weekends must wait to speak with the IHL. As is discussed later in this section, this is especially problematic when discriminatory incidents occur, typically involving staff members and Indigenous patients. These incidents cannot be immediately reported to the IHL and therefore cannot be immediately resolved. By the time the IHL hears about the incident, staff members who were involved are often non longer on-duty, making it difficult or even impossible for the IHL to find out the full picture of what happened. One participant described the challenges associated with this:

I’m not able to find out because a lot of times things and incidents like that are happening at night. And because I’m not here on shiftwork, I’m just here on days, I’m not able to find out all the information that I need. And then I can’t talk to the person that was involved cause usually they’re not working or they’re off or whatever. So I’m not able to find out the other aspect of it. So, I do the best I can to try and you know settle that, but sometimes they just don’t seem to, I’m not able to do that (Participant 3, 17/01/2020).

³¹ This is not to say that this type of discrimination by family doctors does not occur, as other studies have suggested this. However, as this participant does not personally see this as the main problem, it suggests that this type of discrimination may be decreasing, at least in the area this participant works in.

There is typically a social worker available during the night shift if patients require immediate assistance. However, the social worker does not specialize in working with Indigenous patients and patients may feel uncomfortable confiding in this worker about discriminatory incidents, which are very personal. Discrimination is the next major barrier that participants identified and is discussed in detail next.

Discrimination

Discrimination was identified as a barrier by all participants. The findings here are divided into four sections, each describing a different type of discriminatory treatment that participants discussed: Racism and Stereotypes; Ignorance; Indifference; and Perceived Discrimination. Each is discussed separately, with multiple examples provided. Participants were clear that although all types of discrimination act as serious barriers for Indigenous people, the majority of staff members do not exhibit these behaviours. Participants stated that a distinct minority of staff members at their sites engage in discriminatory behaviours. With that said, if even a few staff members act this way towards Indigenous people it is a serious issue that needs to be addressed.

Racism and Stereotypes

Assumptions made by staff members against Indigenous patients is something that Indigenous patients and families frequently encounter within hospitals and has been identified as a problem in the existing literature (Goodman et al. 2017; Hole et al. 2015). Non-Indigenous staff members may hold stereotypes about Indigenous people which then alter the ways that Indigenous patients are treated. These stereotypes are rooted in racism and perpetuate problematic views of Indigenous people. Stereotypes are often internalized and staff members may not be aware that they are making assumptions based on a patient's Indigenous identity.

Stereotype #1: Indigenous People are Bad Parents

According to participants, stereotypes of Indigenous people as bad parents are prevalent in Canada. One participant shared that these stereotypes cause problems when Indigenous children are patients and therefore all interactions with staff members involve the parents. The parenting abilities of Indigenous people may be called into question not because of their actions but simply because they are Indigenous. This stereotype can cause staff members to view things differently – and more problematically – than they would if the parents were non-Indigenous. Participant 2 described an incident where she was called to a unit to speak with a family that nurses suspected were neglecting their child:

On the file it said that they suspected neglect, because a little child was dirty, the ankles were so dirty and stuff like that...So I went and I saw the family and [the mother] was cleaning [the child] up, washing him down and stuff like that, so I thought hmm, didn't look like neglect. And so then I said "Oh my gosh, what happened to your little ankles?" And she laughed and I said that somebody had mentioned that he had dirty little ankles. She said he was out playing, and she said it's a reserve, and I said I know. You know, kids on the reserve, most of them, there's no sidewalks or anything. And the kids actually play in the dirt. So that's an example of them seeing, you know, it's that stereotyping way of thinking (Participant 2, 13/01/2020).

This illustrates how staff members may interpret situations differently when Indigenous families are involved due to internalized stereotypes. Although the child was surrounded by family members and was being bathed by his mother, nurses still suspected neglect. This can make for an uncomfortable situation for the parents and their child, as they may feel they are under closer scrutiny from staff members than non-Indigenous families. It is unlikely that a social worker, for example, would be called to speak with every non-Indigenous family whose child had dirty ankles, but because this family was Indigenous the situation was perceived differently.

Stereotype #2: Indigenous People are Unhygienic

Staff members may also hold stereotypes that Indigenous people are less clean than other patients. One participant shared her thoughts on nurses asking her to speak to Indigenous families about lice:

One thing I get called in for, uh, and I don't know why, well actually I do know why, is when the kids have lice. And I get called in to talk to the family. That's something the nursing team could actually do without me having to say it. And um because when I go and I visit somebody with lice, [the nurses say] "Oh make sure you put on a hairnet", right, and I say you know what? I know they won't fly up to my head, and I'm not going to be touching anybody. You know, it's just, it's carried on further than with other families. And that's the kind of stuff I don't like...And the sense I feel is it's because like [the nurses] feel like Indigenous families are dirty. I'll tell you, it's that stereotype of thinking, it's improved in the last couple years, but still (Participant 2, 13/01/2020).

This participant explained that nurses seem especially concerned when Indigenous patients have lice, as if they are somehow more at fault for having lice than other patients. Viewing patients as dirty, based on their being Indigenous, is pure racism and although this participant acknowledged that things have improved over the last few years, these racist incidents still occur. As another participant commented, "racism is still alive within the health care system." (Participant 5, 29/01/2020). I believe the situation described above exemplifies this.

Stereotype #3: Indigenous People Mistrust Western Medicine

The final stereotype that I discuss is the assumption that Indigenous people are wholly against Western medicine. As seen in the Literature Review, many Indigenous people appreciate access to traditional health care, such as speaking with traditional healers (Auger et al. 2016). Some patients may prefer to utilize traditional health care more than others, however I did not find any studies that suggested that Indigenous patients are likely to refuse all forms of Western treatment.³² Participants explained that they have been requested by unit staff to speak with patients who,

³² Health care providers would need to work with patients on an individual basis if they do feel this way.

according to staff, mistrust the health care system or the Western practices being used. Participant 2 described a situation that illustrated this clearly:

They said that a mum was against um Western medicine, she didn't trust Western medicine, and she'll never trust Western medicine, could I come and just be there and maybe when they explain something to her I can try to explain it to her... I explained to her what I do as the liaison, I'm here for her support, and uh sometimes when we're not understanding things maybe we could sit and work out a plan to be more helpful for you in understanding why, you know, [child's name] needs to be on these medications and stuff, and if you have any questions. And she said "Well, I found something out, [the child] has been spittin' [the medication] out. So that's why, you know, I don't like these procedures!" (Participant 2, 13/01/2020).

The mother in this example did not like the care plan arranged for her child because it was not effective, as her child was not swallowing the medication. The mother tried to explain that she would like a different plan for her child however staff members read this as her mistrusting Western medicine. Participant 2 concluded that, "there was none of this mistrusting. So that was just somebody's interpretation." (13/01/2020). This demonstrates how a normal situation can be misinterpreted due to stereotypical views of Indigenous people. This may make the mother reluctant to point out issues or ask questions in the future, for fear of being misinterpreted. This lends support to the finding that Indigenous patients often feel uncomfortable speaking up.

Ignorance

Ignorance towards Indigenous people and Indigenous culture was identified as another aspect of discrimination that patients encounter. This can be damaging to patients by decreasing both their comfort and the overall quality of their hospital experience. Participants spoke of the ignorance that some staff members have regarding Indigenous cultural practices and the importance these practices have for many Indigenous people. In my experience as a volunteer, most staff members are happy to make arrangements for patients to attend the weekly smudge, even if they do not understand the importance of the ceremony. However, occasionally a staff

member will comment that attending the smudge does not seem like a necessary activity for the patient and will refuse to arrange it.³³

One participant shared that a staff member had recently reached out to her to request smudging services for a patient, however the language the staff member used demonstrated ignorance. She explained, “the other day I had a referral and it was someone requesting “the weed ceremony” [for a patient]. And so I had to address that and kinda put a stop to that way of thinking right there.” (Participant 4, 24/01/2020). Referring to smudging as “the weed ceremony” shows the ignorance of the staff member regarding this aspect of Indigenous culture that is important to many people, including the participant herself. At minimum it is disrespectful and may be upsetting for Indigenous patients and Indigenous staff members to hear an important component of their culture referred to this way. Patients may be reluctant to ask staff members to arrange for them to attend the smudge, as they may worry that staff will say no because they do not respect the ceremony. More broadly, Indigenous patients may feel unwelcome in the hospital if staff display ignorance and disrespect towards Indigenous culture.

Indifference

Indifference can have a direct impact on the care a patient receives. If a staff member displays a lack of concern towards Indigenous patients this can directly and negatively impact the care provided and in turn the overall health of the patient. One participant shared this story involving an Indigenous patient who went to the emergency department with his wife due to severe illness from an infected toe. He was met with disinterest from the attending doctor. The participant described the patient’s experience as a “nightmare in emergency”:

They would not take him seriously, you know, they would just tell him to go home, “Just take him home, get a lot of rest”, and he had a toe infection. And they

³³ Patients who attend the smudge are often on oxygen or have other medical needs that require special equipment, which I am unable to set up as a volunteer. If staff will not assist me I cannot bring the patient to the smudge.

wouldn't even check that, they wouldn't do any tests, blood tests, blood work, even though he was throwing up (Participant 5, 29/01/2020)³⁴

The participant continued:

They didn't know about the Indigenous Liaison. But this was after hours, so the only person that would be there would be a social worker. And they're normally not Indigenous, so there wouldn't be an understanding there. So they also had the same issue at [another emergency department], where the doctor was ignoring him. They kept sending him home but he had to keep coming back because he was getting more and more sick (Participant 5, 29/01/2020).

This highlights the previously discussed issue of IHLs working standard hours, meaning that patients who visit the hospital outside of these hours will not have an IHL for support. The patient eventually found a doctor who was willing to run tests and admit him to the hospital for treatment – but only after several visits to different emergency departments. This suggests that even if Indigenous patients have clear presenting symptoms they may be treated with indifference. The participant explained that the patient's wife eventually told a doctor outright what the problem was, after multiple unsuccessful emergency visits:

[His wife] said, you know, "Look at his toe, it's infected." And the doctor just looked at it, "Oh it just needs to be cleaned." They did not do a proper assessment. The patient was there to get help, so what is a more appropriate way that [the doctor] could have addressed that, right? (Participant 5, 29/01/2020)

The participant commented that the patient's wife had broken down in frustrated tears and the doctor had reacted by commenting that she should seek, "psychological help" (Participant 5, 29/01/2020). This situation provides an example of how the indifference of staff towards a patient can negatively impact not only the patient's physical health but also their emotional and mental health and that of their family members. To use the participant's phrasing, this *nightmare*

³⁴ This immediately reminded me of the story of Brian Sinclair, discussed in the Introduction chapter, and how he was ignored by staff members in the emergency department even though he was throwing up repeatedly and was visibly unwell. This is one of the most well-known cases in Canada of health care professionals showing a lack of concern for Indigenous patients, due to it being such an extreme case of staff neglect. The story told by this participant suggests that Brian Sinclair's treatment – or lack thereof – may not be as rare as many people think.

experience could dissuade the patient and his wife from returning to the emergency department the next time they were in need of care for fear of a similar situation happening again.

Discriminatory incidents like those discussed in the above two sections can be reported to the IHL and can often be responded to quickly. The liaisons can meet with patients to find out the details of what happened and then meet with staff members who were involved to try and work through the incident and prevent it from reoccurring. Although these situations are still harmful to the patient, part of the harm can be mitigated by the IHL, as issues can be resolved so that mistreatment does not continue. However, sometimes incidents occur that the liaisons are unaware of or are unable to help with, as was discussed previously. When incidents occur outside of standard work hours, they may be impossible for the IHL to fully resolve.

Encouragingly, participants agreed that although discrimination against Indigenous people is still an issue within health care, the situation seems to be getting better in general. Changes are happening but the process is slow. However, while discrimination may be decreasing, perceived discrimination remains a common barrier that is difficult to remove, as is discussed next.

Perceived Discrimination

The final type of discrimination discussed is perceived discrimination. According to participants this may be the most common form of discrimination they speak with patients about and can be the most difficult to resolve. There are underlying reasons as to why Indigenous patients may perceive that they are being discriminated against within health care settings and these reasons need to be understood in order to move forward and create changes so that Indigenous patients do not feel this way. Whether a patient is being discriminated against or *feels* that they are being discriminated against, their health care experience will be negatively impacted in largely the same way. Both situations are serious and need to be addressed in order to remove these barriers.

I am not suggesting that discriminatory treatment against Indigenous people does not occur. The participants were also clear about this. Discriminatory treatment does occur, however regardless of this, perceived discriminatory treatment is also a valid concern. One participant expressed this perfectly, when asked whether he thought that discriminatory staff actions were typically intentional or not. He responded, “was it intentional...I can’t answer that, I don’t know. But I know our people feel it was intentional, so that’s what all I can go on.” (Participant 3, 17/01/2020). Regardless of what actually happened in a given situation, if a patient feels that they were intentionally mistreated, that constitutes a negative experience that requires attention. Participants gave examples of different reasons that Indigenous patients may perceive discrimination, which are discussed in order: Anticipation of Mistreatment; Busy Hospital Environments; and Historically-Rooted Discomfort in Hospitals.

Anticipation of Mistreatment

Participants explained that patients may have preconceived notions that they will be mistreated based on previous health care experiences, either their own or those of family members or friends. Because of this, Indigenous patients may overanalyze staff actions and interpret them as discriminatory, in turn negatively impacting their experience. Participants noted that when patients interpret things this way it can influence their behaviour and cause them to act defensively towards health care staff. In turn, this can lead to staff becoming frustrated with the patient which may result in them actually treating the patient differently. This illustrates how perceived mistreatment can potentially lead to genuine mistreatment, while also perpetuating a cycle of mistrust between staff members and Indigenous patients.

Anticipating discrimination can cause patients to avoid health care altogether, even when they need it. One participant noted that this is particularly common in the emergency department,

where mistreatment – as well as perceived mistreatment – is most likely to occur (see Berg 2018; Browne et al 2011). According to the participant, “because of racism and stuff like that, a lot of patients or a lot of people will not come to emergency. Because of the fear.” (Participant 5, 29/01/2020). Patients who have previously been mistreated in the emergency department or have heard about mistreatment from other people may avoid this service altogether. Avoidance of health care can have serious health consequences (Goodman et al. 2017), as health conditions may worsen if not treated and cause further harm to the patient.

Busy Hospital Environment

Hospitals are often busy and stressful environments for patients, staff, and visitors. A stressful environment makes it easier for misinterpretations to occur. Participants agreed that Indigenous patients are more likely to feel ignored or mistreated on busy units. Staff members may not acknowledge patients or may only have a short time to interact with each patient. This is common in the emergency department and ICU, which are naturally high-stress and busy environments. One participant described how this occurs:

I think what happens is a lot of times what happens is because certain units like emergency, like ICU, can get very, very, very busy. And it can get very stressful for everybody. And so if, you know, it comes down to whether they don't have time to pay the attention or take the steps to try to acknowledge the patient. And then, yes, then we got a person who feels that they're being looked down upon because they're Native (Participant 3, 17/01/2020).

This participant explained how these misinterpretations are rooted in the history of Indigenous peoples in Canada and the brutal treatment of Indigenous people throughout colonization. Staff members need to try and keep this history in mind whenever they are around Indigenous patients, as the historical context can drastically and negatively alter how small and seemingly insignificant actions are interpreted. The participant explained:

I mean, the aspect of history is always, that's what I tell the staff, I've told the staff, you know, you've always gotta keep in mind the history. And what's happened over the years. And it's not, you know, our people are going to feel like that. Cause for years, this is what's happened. And if anyone's come out of the residential school and has had no healing, then definitely there's going to be some difficulties there. So that's why anyone working, um, you know that they have to keep a lot of these things in mind. And I can understand that it can be difficult to do that when you're looking after the health, the health of a person too, and there's a lot of stuff going on. So it's trying to manage both at the same time. Which can be difficult (Participant 3, 17/01/2020).

This highlights how historical factors, such as residential school trauma, have shaped Indigenous peoples' perceptions of how they are treated, making it crucial for hospital staff to try and be conscious of their actions. The effects of historically-rooted trauma and mistrust on Indigenous peoples' perceptions of discrimination is discussed in more detail later in this section.

Another participant agreed that staff members in busy units need to make an extra effort to inform patients when they are busy so that patients do not feel purposely ignored. He explained that he frequently tells emergency department staff:

If you guys are busy, and if you have Indigenous patients here, then call me, I'm more than willing to come and explain how busy you guys are and just to be patient, you know. Just that connection, you know, could make a big difference (Participant 5, 29/01/2020).

A small action like quickly checking in with a patient can go a long way in terms of making Indigenous patients feel more comfortable. Participants acknowledged that they understand it can be difficult for health care workers to always keep in mind the history of colonization during busy times. However, staff must make a conscious effort to do this in order to help Indigenous patients feel comfortable in the hospital and prevent issues of perceived discrimination from occurring.

Historically-Rooted Discomfort in Hospitals

An overall feeling of discomfort within health care settings, as has been suggested in previous literature (see Jacklin et al. 2017; Reading and Wien 2013), can contribute to Indigenous

peoples' perceptions that they are being discriminated against in hospitals. This discomfort is often rooted in historical factors, such as lasting trauma from colonial processes. As previously mentioned, the history of colonization influences every interaction that Indigenous people have within health care settings and can lead patients to interpret staff behaviours as discriminatory. Participants spoke about the negative impacts of colonization broadly, however frequently singled out the effects of the residential school system.³⁵

All participants discussed the impact that residential schools had – and continue to have – on Indigenous people. Participants regularly work with patients who personally attended these schools. Goffman (1961) used the term *total institution* to describe situations where individuals are subjected to absolute control over virtually every aspect of their daily life. Residential schools can be described as a total institution based on a number of factors, including: students were physically isolated from their home communities and families; staff members held all the power and students were powerless; and many students experienced severe physical, emotional, and sexual abuse (Rand 2011). Based on this description alone it should be easy to understand how individuals who attended residential school may feel uncomfortable in other institutional settings where staff members effectively hold all the power over, in a health care setting, patients. This explanation from one participant illustrates this:

I think that there's still a lot of apprehension around um, like going to big settings like hospitals, and institutionalized thinking, and things like that, cause like, [Indigenous people] have gone through so much, right? Especially the Elders. Like, I still get people that just bring up residential school, I just had a gentleman recently who brought up his residential school experience, and he cried and cried and cried, right? And he's talking about how he wanted to get out of the hospital (Participant 4, 24/01/2020).

³⁵ For a background discussion of residential schools, refer to the Introduction Chapter (P.8-10).

Although hospitals are obviously different from the total institution of residential schools, all institutional settings can bring back painful memories for survivors and make their experiences in these settings more difficult. Another participant explained that even patients who did not personally attend residential school are still negatively affected by the impacts. As discussed in the Introduction, historic trauma transmission means that Indigenous people who did not personally attend residential school continue to be harmed by its effects (Wesley-Esquimaux, and Smolewski 2004). One participant explained that, “[Indigenous people] are known to carry the impact of colonization, even if we’ve not been in residential school. I’ve not been to residential school yet I’m of age to be. And so I still have the impact of that to this very day.” (Participant 1, 10/01/2020). While residential school survivors may be especially uncomfortable in institutional settings, other Indigenous people may also experience discomfort due to their knowledge of residential schools or their personal relationships with survivors.

The reluctance to speak up to hospital staff has been discussed throughout this chapter as well as in the Literature Review. This reluctance may partially be the result of residential schools where Indigenous people were punished for speaking up. A participant shared her perspective:

They don't know how to ask for help...they don't even know that they could ask because of how the government has always controlled everything. There's an expectation to be helped, to be fed, to be housed, because they have been, they haven't been allowed to be freely independent or speak up because of government control, it's the Indian Act that controls everything (Participant 1, 10/01/2020).

Based on this it is understandable that Indigenous people may feel voiceless in the hospital and often rely on IHLs to speak to staff on their behalf. The participant’s point that “the government has always controlled everything” is important to note because it is something that many people are unaware of. The Canadian government-imposed control over Indigenous people; this was not a choice that Indigenous people made. Because of this it is reasonable that Indigenous

people may not ask for help because they expect that all decisions regarding their care have already been made for them.

Summary

The findings presented in this section answer the second research question by discussing barriers that participants identified based on their experiences working with Indigenous patients. These barriers are summarized in Table 2 (below). Some of the barriers identified are systematic, in that they are related to policies within the health care system. Access barriers, such as transportation, issues with NIHB, and a shortage of family doctors, are all systematic barriers that result from organizational and policy issues within Alberta Health Services and, in the case of NIHB, the federal government. Participants also identified personal barriers, which are related to individual actions and perceptions. Racism, stereotyping, ignorance, and indifference towards Indigenous patients are personal barriers that result from the actions and attitudes of individual staff members. Perceived discrimination is another personal barrier, in that it occurs when an individual patient’s own expectations for their health care experience are not met. Identifying barriers is necessary to understand what areas of health care are most problematic for Indigenous patients. Once these areas are understood the focus can shift to finding solutions to actually remove the barriers. The next section in this chapter highlights some of the existing resources and initiatives within Alberta Health Services that are beneficial for Indigenous patients and can help to alleviate some of the harm caused by barriers.

Table 2: Barriers Identified by Study Participants, 2020

Systematic/Policy-Related Barriers	Person-Related Barriers
<i>Access Barriers</i>	<i>Discrimination</i>
Transportation	Racism and Stereotyping
Issues with the NIHB Program	Ignorance
Limited Access to Family Doctors	Indifference
<i>Challenges of the IHL Role</i>	<i>Patient Interpretations</i>
Standard Work Hours	Perceived Discrimination

Source: Link, *Indigenous Hospital Liaison Study, 2020*

Highlighting Existing Resources

The findings presented in this section provide examples of resources within Alberta Health Services that are beneficial for Indigenous patients, from the perspective of the participants. These findings address the third research question: What existing resources or services do Indigenous Hospital Liaisons highlight as beneficial to Indigenous patients? This section incorporates the principle of *envisioning* by highlighting resources with positive impacts (Tuhiwai Smith 2012). Sharing success stories of existing resources could help protect them from future funding cuts. Additionally, other organizations may read about a successful resource and attempt something similar. However, resources with positive impacts may still benefit from additional modifications.

Useful resources are discussed in this section along with feedback participants mentioned for further improving these resources. This section also includes positive comments that participants made about dedicated staff members at their sites taking initiative to help Indigenous patients. Although staff initiative is not technically a resource it can have positive impacts for patients and therefore is relevant to this discussion.

Weekly Indigenous Smudging Ceremonies

The weekly smudging ceremony has been mentioned several times in this chapter and therefore is only briefly discussed here. All participants spoke highly of this ceremony, as it has not always been available in hospitals. Few studies in the Literature Review mentioned smudging or other Indigenous resources that were available to patients, suggesting that these resources were either not available or at least not well-known among patients.³⁶ Many people seem more relaxed and in generally higher spirits following the ceremony.³⁷

³⁶ Goodman et al. (2017) mentioned that a smudging room was available at the health care site they were studying, however it was always locked and only a few staff members had access, therefore limiting its usefulness to patients.

³⁷ I have personally observed this as a volunteer at the ceremony. Many patients have expressed to me how much the smudge has helped them and have asked me to pass along their thanks to the facilitator of the smudge.

Mandatory Staff Training

Alberta Health Services staff members must take mandatory online training modules on Indigenous Awareness and Sensitivity.³⁸ Staff members have three years upon being hired to complete the modules; staff members who were already employed with Alberta Health Services prior to the modules being introduced just over two years ago have three years from the date of the program launching (Southwick 2019).³⁹

The program includes three topics, each broken down into modules. They are: Our People (1A, 1B, and 1C); Our Culture (2A and 2B); and Our Wellness (3A and 3B). Each module consists of slides that provide a considerable amount of information about the respective topic. The slides also include links to videos and other learning materials. Each module ends with a list of additional resources. “Our People” provides background information about Indigenous people in Canada, with a focus on Alberta. Information is provided about the different First Nations in Alberta, as well as information about the three Numbered Treaties that cover the land in Alberta. “Our Culture” focuses on Indigenous cultural and spiritual practices, and includes discussions of smudging and sweat lodges⁴⁰, for example. “Our Wellness” shifts the focus from background information to discussing how Indigenous people experience health and health care today. This topic includes examples of situations that health care workers may encounter when working with Indigenous patients, along with examples of how to provide appropriate care in these situations.

³⁸ Although I volunteer at an Alberta Health Services hospital, the training is only intended for staff members; volunteers are not required nor typically given the opportunity to complete these training modules. I was given permission to participate as part of this research.

³⁹ There have been concerns that many doctors are exempt from the program due to their being independent contractors within Alberta Health Services (see Southwick 2019), however these kinds of issues were not the focus of this study, and participants all spoke about this program as though it were mandatory for all staff members.

⁴⁰ Sweat lodge ceremonies help cleanse and heal the body, enabling participants to think clearly. They also provide a spiritual place for Indigenous people to connect with the universe and gain Elder’s teaching in a traditional way (Native Counselling Services of Alberta 2020).

Each module takes about 45 minutes to complete, however there are multiple videos and other additional materials that staff members can optionally explore.

All participants spoke positively about the online training. They agreed that it provides useful information about the history of Indigenous peoples in Canada as well as information on cultural practices like smudging. Certain aspects of history, such as the legacy of the residential school system, are still unknown to many staff members and participants were glad that staff were now able to learn about, “a part of history that is still so hidden.” (Participant 4, 24/01/2020).

Participant 3 explained that he has already seen a difference since the program was introduced:

There's actually been a lot of difference, and I actually had a couple people come and tell me that they've had a good, it's been a good like light for them, and they've realized things or they've learned a lot. So, that's been a positive for the program (Participant 3, 17/01/2020).

It is encouraging that this participant has observed changes soon after the program's introduction. However, while participants agreed that the online training was a good thing, some pointed out an unintended consequence. One participant explained:

Since [the introduction of the training program] I've had an overwhelming response in referrals. Because, this is what I think, staff are thinking that if they automatically submit a referral, in their minds that is a culturally sensitive approach. And I cannot keep up with these referrals. So it's very unfortunate because it's a disservice, it's a disservice to people because I'll see them once and never see them again. They don't know the reason [for the referral], there is no additional information, they just pop it off, done, check (Participant 1, 10/01/2020).

Not all Indigenous patients have the same needs and therefore not all will benefit from the same services. Staff members who assume that all Indigenous patients would like to speak with an IHL are making broad generalizations, which can be problematic. The massive increase in referrals means the IHL has less time for each patient. When many referrals do not include relevant information – because the staff member did not check in with the patient first – that adds an even larger time burden for the liaison.

Staff members may have good intentions when doing this, however it shows that they do not truly understand what it means to take a culturally sensitive approach with Indigenous patients. They do not recognize that each patient is unique and therefore a one-size-fits-all approach, such as automatically referring Indigenous patients to the IHL, is not appropriate. Participants suggested that the online program could benefit from modifications to incorporate more applied elements so that staff can better connect their learning to their work. Previous research has suggested that Indigenous cultural training programs in health care are not useful if the information is decontextualized and staff members cannot directly apply it to their work (Berg 2018; see also Vass 2015). Ensuring that the information presented has clear and relevant connections to health care may help staff better understand what culturally sensitive – and culturally safe – care involves.

Dedicated Staff and Staff Initiative

Although participants identified discriminatory behaviours exhibited by individual staff members as a barrier encountered by Indigenous patients, they generally spoke highly of staff members at their sites. Some of their positive comments are shared first before discussing one example of staff initiative.⁴¹ One participant shared that many unit managers at her site are appreciative of the IHL program and always want to learn more about Indigenous culture:

That's something that like most of the unit managers at my site are really good that way, like they want those kind of things, like I did a smudging for an entire unit like a month ago. Right, so I think they're really willing to incorporate those kind of teachings (Participant 4, 24/01/2020).

This participant was impressed with the willingness of the unit managers to learn more about Indigenous practices. This quote also provides an example of staff initiative: a unit manager

⁴¹ Several participants expressed that they did not want to paint an inaccurate negative picture of staff at their site and that they wanted to highlight the staff's many strengths.

reached out to the IHL to request a smudging ceremony for an entire unit. This was not mandated by Alberta Health Services but was something that the unit manager organized on their own.

Participant 5 commented that the quality of care towards Indigenous patients at his rural site is generally quite high:

I think here at [specific site] everybody is doing their best, um, with providing services to Indigenous people. And there are staff here that are very genuinely concerned with caring for patients, I've seen it, um, which I'm really happy to see. So I hope that that will spread, to all staff, everywhere (Participant 5, 29/01/2020).

This participant felt that part of the reason that staff at the rural site were able to provide high quality care was because the site is smaller and generally less busy than the urban sites.

However, several urban participants were also impressed with the care at their sites:

[Staff] are very accommodating with, you know, they try to help out as much as possible, I've seen nurses bring in, I mean, I guess I'm not going to say they're doing it particularly because you know for our people as Aboriginal people, but I've seen them bring in stuff like shampoos or something, stuff for a particular patient, including Aboriginal patients, that could happen with everybody but it still shows they care...yeah, they do the best they can to help out if they can (Participant 3, 17/01/2020).

These comments emphasize that, according to participants, the majority of staff members at their sites are committed to providing a high quality of care to all patients.

Participants also discussed examples of staff members taking initiative to help Indigenous patients have a better hospital experience. I focus here on the initiative that all five participants spoke about, specifically staff setting up smudging services for patients without the involvement of IHLs. One participant explained:

I've seen [staff] move patients, especially in ICU, if they can move a patient into a room that they can shut the services down for a smudge. So a family can you know do the smudge and healing ceremony in that room, I've seen them do that. I've seen them you know of course take the initiative, they've taken the initiative to set things up themselves about setting up the smudge, phoning down to security, getting them to get the maintenance to shut down the particular services to whatever room, so (Participant 3, 17/01/2020).

This can also benefit the IHLs by giving them more time to respond to other kinds of referrals. Participant 1 commented:

Staff set up the room [in ICU] without my presence, because [the family] has already brought an Elder or a family member that can facilitate all of that for the family, so it's done in ICU without my involvement, which is good because it frees me of time. And a lot more staff now initiate and encourage smudging in the rooms, without my involvement (Participant 1, 10/01/2020).

This participant was pleased with the initiative of staff members in the ICU and was happy that this enabled her to focus her time on other tasks. Given the large numbers of referrals that IHLs often get, it is a benefit if staff members are able to ease some of burden by taking over tasks like this. This participant also expressed that staff at her site are increasingly offering Indigenous patients the opportunity to smudge in a private room even if the patient is not at end-of-life. Normalizing smudging and recognizing it as a regular aspect of many Indigenous peoples' lives shows that staff members are becoming more familiar with Indigenous culture and practices and suggests that staff are becoming more culturally competent in general (Baba 2013).

The Importance of Indigenous Hospital Liaisons

All participants explained, in their own words, the importance of their role and why their position is beneficial for Indigenous patients. Participants spoke with pride about the work they do and expressed that the existence of their position shows that Alberta Health Services is taking steps to improve health care for Indigenous people. In this section I have tried to emphasize the principle of *representing* by providing a positive image of Indigenous people by highlighting the value of IHLs (see Tuhiwai Smith 2012). Participants' comments that are shared here should not be read as participants bragging about themselves but rather recognizing the value of their role.

Participants were asked to share what they would like patients and staff members to know about the IHL role. Three responses are shared below to highlight key features of the role, in participants' own words:

I think it's important for people to know that we're here for their support, we're here for their voice, and um that we actually are on their journey with them, that we can do our part, I can't do everything for them, there's some things that I will direct them to but we can help, we can help them make connections to the systems that you want to be in. We can help them so that they feel respected and you know that this is what you can do for us, that they know they are a part of the team, and that they're more than valuable to us (Participant 2, 13/01/2020).

This response exemplifies the commitment that IHLs have to patients. The language that this participant uses, such as being “on their journey with them” and that “they're more than valuable to us” in reference to Indigenous patients is powerful and shows how meaningful the IHL position is to her. Another participant responded:

Just know that we're here to help. We're here to assist both sides. We assist the staff in understanding and dealing with the personal care needs of the patient. And the patient needs to know that we are here to help them if we can, assist them with connections, with resources. So, it's knowing that we're here, that's the basic thing I can say, having that knowledge that we're here to help, if we can (Participant 3, 17/01/2020).

This response is a reminder that IHLs can help staff members as well as patients. They are “here to assist both sides” and can be utilized by staff who are trying to ensure that they provide the most beneficial care they can for patients. This is important for staff to realize so that they can proactively seek out the assistance of the IHLs, instead of relying on patients to make the first move and request a referral. The final response I will share is:

I think the most important thing that the hospital should know about my role is the value of it. Um, identifying the value in working with me. How identifying the value and working with the liaisons is a positive outcome to the patient because they're gonna take that to their home community that they've had a positive experience, right?...So, you look at someone who has been here fifteen years ago, in a unit where I don't work a lot, and they come back on another unit and they say “Well I

wish I'd have known about you fifteen years ago. And they're ever so grateful. So that helps to build trust (Participant 1, 10/01/2020).

This exemplifies the powerful impact that IHLs can have. When patients work with these individuals they may tell their friends, family, and other community members about their positive experiences. This can help build trust within the community and decrease the apprehension that many Indigenous people feel towards the health care system. Just as previous negative experiences, both personal and those of friends or family members, can make Indigenous people fearful of health settings, positive experiences may help ease their worries and make them more comfortable accessing health care. If they know an IHL is available they may be more confident as patients, knowing they can get help if they need it. Breaking down the mistrust that many Indigenous people have towards health care will take time, but IHLs are helping this process move forward.

In a recent review of health initiatives intended to improve cultural safety for Indigenous people in Canada, Brooks-Cleator, Phillips, and Giles (2018) identified six themes for culturally safe programming. The themes are: Collaboration/Partnerships, Power Sharing, Addressing the Broader Context of the Patient's Life, Safe Environment, Organizational and Individual-Level Self-Reflection, and Training for Health Care Providers. The IHL program is a culturally safe health initiative that aligns with each theme, as the following examples illustrate.

1. IHLs regularly work with patients, families, community members and organizations, and hospital staff, and build trusting relationships with individual patients, demonstrating the first theme.
2. IHLs empower patients to express their needs and wants and make decisions regarding their own health and health care experience, encompassing the second theme.
3. Through holistic consideration of a patient's needs, IHLs recognize the full context of a patient's life beyond only their medical needs, demonstrating the third theme.

4. They provide patients with a safe and non-judgemental environment by urging patients to express their questions and concerns freely, and assisting patients to safely engage with their culture and spirituality through services such as smudging, aligning with the fourth theme.
5. Theme five is fulfilled as IHLs reflect on both positive and negative aspects of their individual care sites as well as Alberta Health Services as a whole, which demonstrates organizational self-reflection. They also reflect on their own actions and decisions to ensure they are acting in a way that is most beneficial to the patients they work with.
6. Finally, the sixth theme is demonstrated as IHLs assist in the continuous training and education of hospital staff with regards to the history and health of Indigenous peoples in Canada by answering staff questions and correcting problematic behaviours and ways of thinking.

Summary

The findings in this section have answered the third research question by illustrating services that currently benefit Indigenous patients. Multiple resources were highlighted, suggesting that Alberta Health Services is striving to ensure that Indigenous people receive adequate health care. The final section in this chapter explores additional resources and changes that participants suggested to further improve patients' experiences.

Next Steps

This final section shares participants' recommendations for improving health care for Indigenous patients. These findings are used to answer the fourth research question: What additional changes would Indigenous Hospital Liaisons recommend to Alberta Health Services to improve the experiences of Indigenous patients? The recommendations are grouped into three

categories: Cultural Resources; Furthering Staff Education; and Expanding the Indigenous Hospital Liaison Program. Cultural Resources are discussed first.

Cultural Resources

The importance of culture to many Indigenous patients has been discussed throughout this chapter and was stated several times by all participants. Some participants mentioned that in addition to smudging ceremonies many patients would appreciate if sweat lodges were made available. One participant described a pilot program that her site had tried where a sweat lodge was available on-site. She commented:

I think that was really good for patients and for healing because [sweat lodges] are hard to find, right? I think it's good that our program did that...I have patients all the time ask me or tell me they want to reconnect but they don't know how. So then I have to try and find an Elder, "Hey do you know any sweat lodges coming up, I have a patient." And then the person has to try and get there (Participant 4, 24/01/2020).

This participant was unsure of whether the program would be brought back but felt that it would be useful to have again. This may be a particularly beneficial resource for urban hospitals. Participants explained that patients frequently ask if there are any sweat lodges in the area that they can attend. Most sweat lodges are hosted on reserves and patients who wish to attend must find their own way there. Transportation was already discussed as a barrier for many Indigenous people, and many patients cannot find a way to attend a ceremony on a reserve. Having an on-site sweat lodge in an urban area was something that patients were appreciative of during the pilot program and, according to participants, could benefit patients' healing.

Although cultural resources are wanted by many patients, not all Indigenous people practice traditionally and therefore resources beyond those related to culture are also needed. This will ensure that Indigenous patients who follow different practices or ways of living are still able

to benefit. The next two resource categories that are discussed are not directly related to Indigenous culture and are therefore relevant to all Indigenous patients, regardless of their cultural beliefs.

Staff Education

Although all participants spoke positively about the Indigenous Awareness and Sensitivity online program they also made suggestions for furthering staff education. Blanket exercises were brought up by several participants as an educational tool that is complementary to the online program. KAIROS blanket exercises were developed in response to the Royal Commission on Aboriginal Peoples final report in 1996. In this report, increasing education about the history of Indigenous peoples in Canada was identified as an important step towards reconciliation (KAIROS Canada 2019). Although most of the same information is included in the online modules, the level of detail is greater in a blanket exercise. These exercises are interactive, as trained facilitators use detailed descriptions and physical space to literally walk participants through the history of colonization, showing the loss of land, resources, and people, while highlighting the resilience of Indigenous people throughout history. The interactive element makes it easier for participants to retain what they have learned, as Participant 4 explained:

It makes [the information] more tangible, something you can see, like, it's more interactive, so people actually are forced to pay attention and learn it, whereas opposed to sitting and staring at the computer screen and trying to retain that, right? (Participant 4, 24/01/2020).

I have personally participated in a blanket exercise put on by Alberta Health Services and it was very impactful. Many participants are able to connect to the history on an emotional level that is typically not possible through simply reading the information, which can make the material more meaningful. Participant 2 commented:

They offer a lot of insight, and I think that, no matter how the entire blanket exercise goes, I always hear at the end a kind of a general consensus that they all say, "Well, I never knew this", right? Or they're very grateful that they can go home and hug

their kids at night, like it's those small things that people didn't, like people take for granted every day that I think the blanket exercise sheds a lot of light on (Participant 4, 24/01/2020).

Although it is not required for IHLs, two participants are trained as facilitators and can put on these exercises on behalf of Alberta Health Services. These exercises are sometimes put on for staff, although attendance is not mandatory as it is with the online program. One participant suggested that blanket exercises be made a mandatory component of staff education; other participants felt that blanket exercises should be offered more frequently to staff but that participation should be voluntary. Participants who do not personally facilitate blanket exercises agreed that they are very educational and can be highly impactful for those who attend.

Participants also spoke about additional resources that have recently been made available to staff members to further their knowledge of Indigenous peoples' history and traditional practices. Opportunities to attend sweat lodges have recently become available to all Alberta Health Services employees, enabling staff to gain insight into what is an important ceremony for many Indigenous people. The weekly smudging ceremony is also always open to staff members, provided that the timing fits into their schedule. Participants expressed that these opportunities are beneficial for staff members and should be offered more frequently.

All additional events and learning opportunities are optional, with the online program being the only mandatory aspect of staff education. Participants generally did not feel this was a problem however, and several commented that they have seen staff members taking initiative to seek out further education. One participant explained that he had recently been asked by nurses at his site to give a presentation on Indigenous politics and how the local Chief and Council system worked in a nearby First Nation. He was happy to do so and was pleased that the nurses had shown initiative by reaching out to him. Other participants commented that since the online program was

initiated, staff members regularly ask them questions about colonization in Canada. This demonstrates that staff members are becoming more interested in learning about Indigenous people, and hopefully suggests that they will use what they learn to inform their work and provide more appropriate care to Indigenous patients.

Expanding the Indigenous Hospital Liaison Program

In speaking with the IHLs it became clear that while they are content with their work they are almost always busy and often have more to do than is possible for one person. I have mentioned this previously and shared the comments of one participant who talked about the overwhelming increase in referrals since the introduction of the online training. Having a second IHL at one site could be a benefit, especially in larger sites when one person cannot possibly respond to every request on time. One participant explained:

Having more liaisons on staff would be good for sure, especially in the mental health area that I cannot always get to. I probably have, here's an example, I probably have five [patients] here that I've seen once this week and won't see again, just because there are always new patients...And I may have a list [of patients] to follow, but there are all the phone calls that I add on. Or the people that come seek me out. So having another liaison is something that would be really useful (Participant 1, 10/01/2020).

Multiple participants mentioned that mental health units often have many referrals and that these referrals are often more complicated and take more time. Having an additional IHL could enable one person to dedicate themselves to the mental health units, ensuring that all patients who want IHL services can get them in a timely manner.

Another issue that I discussed previously is that IHLs only work regular hours. Participants acknowledged that many patients who would benefit from their services come to the hospital after hours, often through the emergency department. One participant commented:

So when someone comes into crisis at [the hospital], let's say there's a car accident, you gotta wait 'til Monday. Right? It's not really fair. So I think that we

could improve, that would be a good improvement, if we could have more, like, someone to cover casual or on-call (Participant 4, 24/01/2020).

In a later interview I asked another participant what their thoughts were on possibly introducing an on-call IHL to cover things after hours. He responded:

Oh God yes, that's what we need! The units are chomping at the bit for that, emergency especially, they're chomping at the bit for us to have one, they need one. So yeah there's definitely a need (Participant 3, 17/01/2020).

This reaction demonstrates that this service is wanted not only by the IHLs but by entire units within hospital, particularly emergency departments. There are multiple reasons that the emergency department in particular would benefit from an after-hours IHL. First, Canada has a high rate of after-hours emergency department use (Kiran et al. 2018). Second, research suggests that Indigenous people may use the emergency department at higher rates than the rest of the population (Berg 2018; Dell et al. 2015), and multiple participants commented that many Indigenous patients at their site are admitted through the emergency department. And finally, the emergency department is often the site of discrimination and perceived discrimination, as participants discussed and previous studies have suggested (Berg 2018; Browne et al. 2011). I mentioned that one participant commented that Indigenous people may avoid the emergency department when they need care because of the expectation that they will be mistreated. Having an on-call IHL, or alternatively an additional IHL specifically for the emergency department, could greatly benefit Indigenous people.

Summary

The findings presented in this final section have answered the fourth research question. These findings demonstrate that although Alberta Health Services has made progress, Indigenous patients could further benefit from additional programming. The final chapter builds on this section, providing specific recommendations for Alberta Health Services to consider.

Chapter 5: Conclusion and Recommendations

The findings of this research have answered the four research questions. Each question was linked to one of the four goals of this research: to explore the role of IHLs within Alberta Health Services; to understand the barriers that IHLs identified as common for Indigenous patients; to share the positive impacts of existing resources; and to determine what additional resources or changes may further benefit Indigenous patients.

To answer the first question, detailed insights from current IHLs were provided. IHLs are unique within Alberta Health Services due to the holistic approach they take to health care, which ensures that all of a patient's needs are addressed, not just their medical needs. They commonly provide communicative services to improve understanding between patients, families, and staff members. This includes translating medical terminology into more understandable terms for patients and helping patients' express their questions and concerns to staff members. IHLs also provide smudging services to help Indigenous patients meet their spiritual needs, and do their best to help meet the needs of patients who do not practice traditional Indigenous forms of spirituality. These services help Indigenous patients have a better experience in the hospital.

The second research question was answered by discussing barriers that the IHLs believed were commonly encountered by Indigenous patients when accessing health care in Alberta. Some of the barriers identified were systematic barriers related to health care policies and organizational issues. Systematic barriers were primarily related to accessing health care and included issues with hospital-provided transportation, problems with the NIHB program, and a shortage of family doctors in Alberta. IHLs help patients work through these barriers, however due to the standard hours they work – another systematic barrier – they are not always available to help. Other identified barriers were personal, arising from the individual actions of staff

members and the personal perceptions of Indigenous patients. Issues such as racism, stereotyping, ignorance, and indifference towards Indigenous patients are all examples of personal barriers that result from the actions and attitudes of individual staff members. Other personal barriers result from patients' own perceptions of their treatment within the hospital and whether or not their individual expectations were met. Patients' interpretations are influenced by a number of factors including their previous health care experiences and whether the hospital is particularly busy at a given time. Indigenous patients may also feel a general discomfort in hospitals due to trauma rooted in colonization, which can influence their perceptions of the treatment they receive.

Systematic and personal barriers create challenges for Indigenous patients. The IHLs in this study try their best to help patients navigate these barriers, however real changes are needed in order to actually remove these barriers. Systematic and personal barriers require different solutions and an in-depth understanding of these barriers is needed before solutions can be determined. The findings used to answer the second research question provide useful information about these barriers, however additional details are needed to ensure that these barriers are fully understood.

The third research question was answered by highlighting existing resources that IHLs identified as beneficial for Indigenous patients. The weekly smudging ceremony held at many sites is one such resource. The existence of this resource demonstrates that Alberta Health Services is working to improve health care for Indigenous patients. Participants pointed out that smudging has not always been available in Alberta hospitals and is appreciated by many Indigenous patients and families. Alberta Health Services has previously recognized the importance of spirituality and prayer for many patients and family members (AHS Spiritual Care

Advisory Committee 2015) and it is encouraging that they recognize smudging as an important aspect of this for many Indigenous people. The weekly ceremony is typically hosted by a Traditional Wellness Worker, who is also available to respond to individual patient requests and provide personal spiritual services. The willingness of Alberta Health Services to have positions like Traditional Wellness Workers that are dedicated to helping Indigenous patients meet their spiritual needs suggests that the health care system is becoming increasingly accepting of Indigenous health practices.

Another beneficial resource is the mandatory Indigenous Awareness and Sensitivity online training, which helps staff members become familiar with the history of Indigenous people in Canada so they can provide appropriate care. The IHLs have already observed positive changes since the introduction of this program two years ago, such as staff members showing initiative to enable Indigenous patients to smudge more frequently. The creation of this mandatory program demonstrates that Alberta Health Services recognizes that Indigenous people in Alberta have unique health and health care needs that must be appropriately addressed. A one-size-fits-all approach is not acceptable and the history of Indigenous people in Canada needs to be understood to ensure that culturally sensitive care can be provided.

The existence of the IHL program is perhaps the best example of Alberta Health Service's commitment to improving health care for Indigenous people. These individuals are highly valued within the health care system and can help to significantly improve the experiences of Indigenous patients (Berg 2018). The existence of the IHL program, which aligns with previously identified themes of cultural safety (Brooks-Cleator et al. 2018), again demonstrates that Alberta Health Services recognizes the unique health and health care needs of Indigenous people.

Although Alberta Health Services has demonstrated an interest in improving health care for Indigenous patients, additional changes are needed. The fourth and final research question addressed the need for additional improvements and was answered by sharing participants' recommendations for changes that may further benefit Indigenous people in hospitals. Expanding cultural resources to include ceremonies such as sweat lodges was one suggestion that participants felt would benefit Indigenous patients. Increasing opportunities for staff education was another suggestion, with blanket exercises being recommended by several participants as a particularly useful educational tool for staff members. Expanding the IHL program was another suggestion that all participants spoke about. As beneficial as the IHL program is, participants agreed that it could be improved by having more IHLs available to help Indigenous patients, or having IHLs who work outside of regular hours.

Based on the suggestions of participants, as well as the overall findings of this research, I have developed specific recommendations for Alberta Health Services to consider. These recommendations are specifically intended to improve the experiences of Indigenous patients in Alberta hospitals.

Recommendations

I have formulated two areas of recommendations for the Indigenous Health Program and Alberta Health Services to consider. The first set of recommendations relate to expanding the IHL program while the second set relates to furthering staff education. These recommendations may not be currently feasible, financially speaking, for Alberta Health Services. However, I provide them here so that they may be referenced or considered in the future, especially if Alberta Health Services restructures their budget in the coming months (see Fieldberg 2020).

Recommendation#1: Expand the Indigenous Hospital Liaison program.

The IHLs in this study are a significant benefit to the patients they work with. However, not every hospital currently has an IHL in any capacity. I recommend ensuring that each hospital has an IHL. If this is not feasible, as some rural hospitals are quite small, I recommend having a full-time IHL in rural hospitals located nearest to First Nations communities, which are likely to have many Indigenous patients, and part-time or on-call liaisons available to visit the other hospitals as needed.

Large hospitals that currently have an IHL may benefit from having an additional IHL. Participants noted that due to high demand they are not always able to provide adequate services to all interested patients, as there is only so much that one person can do in a day. I recommend adding an additional full-time IHL for large Alberta hospitals to ensure that more referrals can be responded to and that IHLs can spend as much time as needed on each referral. Participants commented that mental health units often have a large number of referrals, for example, and having an additional IHL could enable one to focus on these units while the other responded to other referrals.

I recommend having on-call liaisons available to assist patients after-hours and on weekends at all sites. This would be a benefit to patients and staff members. This service would be especially useful for large sites with high rates of after-hours emergency department use. I also recommend adding emergency-department specific IHLs at the largest hospitals. This would ensure that patients in emergency departments, which are often the site of discrimination and other issues, could receive assistance when they need it. Additionally, this would enable the primary IHL to focus on other units, freeing them of time and ensuring that they are able to respond to their other referrals in a timely manner.

Recommendation #2: Review the mandatory staff training to align with cultural safety.

The mandatory Indigenous Awareness and Sensitivity online program is a useful way to increase staff members' knowledge of the history of colonization and Indigenous peoples in Canada. However, participants pointed out that some staff may not truly understand what it means to take a culturally sensitive approach when working with patients. I argue that cultural sensitivity alone is not sufficient and that the training should be modified to incorporate elements of cultural competence and cultural safety.

As discussed previously, cultural sensitivity focuses on respecting patients' cultural differences, while cultural competency and safety go further and consider cultural differences in relation to health care provision (Baba 2013). Cultural safety specifically requires staff members to critically reflect on power imbalances between themselves and their patients and is evaluated by patients to determine whether or not cultural safety was achieved (Baba 2013). Cultural safety should be the goal of the online program to ensure the most beneficial care for Indigenous people.

An Alberta Health Services report explained that Cultural Safety Improvement projects have recently taken place to provide a starting point for individual hospitals to launch their own cultural safety initiatives (Berg 2018). Another report suggested that creating a cultural safety framework is a goal of Alberta Health Services and is currently in development (Davachi and Wuitschik 2013). Based on this, I recommend that Alberta Health Services review the existing Indigenous Awareness and Sensitivity training program to incorporate more explicit ties to cultural safety. Resources from the Nursing Council of New Zealand may be useful in restructuring the online program (see Nursing Council of New Zealand 2012).

Participants mentioned that it can be difficult for staff members to always keep the history of colonization in mind when they are around Indigenous patients, but emphasized that this is

critical. I recommend altering the online program to emphasize the relevance of the historical information to Indigenous peoples' health today and the actual provision of health care. Making clear links to staff members' work will increase the likelihood of staff keeping the information in mind as they work (Vass 2015), again enhancing cultural safety for Indigenous patients.

Moving Forward: Future Research Possibilities

This study provides a useful starting point for future research to build off due to its unique in-depth focus on the insights of IHLs. I am hopeful that other researchers will recognize the integral role that these individuals occupy within Alberta Health Services and how they help to improve health care for Indigenous patients. I include here two suggestions for future researchers to consider. With all research of this type it is important to keep in mind that the goal should ultimately be to benefit Indigenous people (see Kovach 2009 and Tuhiwai Smith 2012).

Research Suggestion #1: Include a larger number of Indigenous Hospital Liaisons.

Similar to this current research, a multiple case study should be conducted with a greater number of participants from different acute care sites in Alberta. In particular, the inclusion of more rural sites would be a benefit. This would enable comparisons to be made between urban and rural sites, which may highlight the need for different resources for each site. This current study only included five hospitals, four urban and one rural, meaning any observed differences between urban and rural sites are based on a very small sample, preventing generalizations from being made. Including more IHLs could also provide insight into additional site-specific resources that benefit Indigenous patients, which could then be adapted and incorporated into other sites.

Research Suggestion #2: Include Indigenous Hospital Liaisons as co-researchers.

There are multiple directions that research could take if IHLs were included as co-researchers. Future researchers should build strong relationships with the IHLs so they can

collaboratively design research to benefit Indigenous people. This would ensure that the research reflects what the IHLs consider to be important topics or research goals.

Involving IHLs as co-researchers also presents an opportunity to include Indigenous patients. This is similar to the approach taken by Cameron et al. (2014a and 2014b), where CHRs conducted interviews with patients in the emergency department. Patients often feel immediate trust with the IHLs which may help patients feel more comfortable when discussing their personal health care experiences. Including patients would confirm whether the barriers identified by IHLs in this study are the same barriers that patients identify, or if there are additional barriers that patients find problematic. This would also be in keeping with the principles of decolonizing research, which advocates for Indigenous-led research to ensure that Indigenous perspectives are centred (Tuhiwai Smith 2012).

Limitations

Although this study contributed novel findings through its in-depth focus on Indigenous Hospital Liaisons, two limitations should be addressed.

First, as discussed in Chapter 3, this study has a small sample size. Five IHLs and one Traditional Wellness Worker participated for a total of six participants. Not all areas of Alberta are represented in this study and of the five hospitals included only one was rurally located. Findings may not be applicable to all Alberta hospitals.

Second, Alberta Health Services is unique in that it provides health care to all of Alberta. Other provincial health care systems are divided, with different systems serving different areas or specializing in certain services. Findings from this study may not be applicable to other geographical areas with other health care systems. Resources highlighted as beneficial to Indigenous patients may not be possible in other areas or within other health care systems.

Contributions to the Existing Literature

Despite these limitations this thesis presents original and important findings regarding health care for Indigenous patients in Alberta. It has helped fill several identified gaps in the literature, the first being a geographical gap. This research builds on previous studies that have investigated health care barriers in other provinces, particularly British Columbia, to provide context-specific findings relevant to Alberta Health Services. The second gap identified was a limited focus on positive experiences and possible solutions, which can lead to deficit discourses about Indigenous people being perpetuated. This current research is a strength-based study that incorporates positivity in three ways: emphasizing the work of IHLs; highlighting effective resources available to Indigenous patients in Alberta hospitals; and focusing on moving forward by considering additional changes that may benefit Indigenous patients. Finally, this research has helped fill a gap in the literature by focusing on the insights of Indigenous health care workers, which few studies have done previously. This contributes a new perspective to the Indigenous health literature and highlights the important role that IHLs will continue to play in improving health care for Indigenous patients in Alberta.

The findings of this study are particularly relevant given the current situation in Alberta, with Alberta Health Services facing significant cuts in funding (Fieldberg 2020). Highlighting the benefits of IHLs could help protect this program from funding cuts, which is essential if Indigenous patients' health care experiences are to improve. If budget restructuring decisions need to be made, the recommendations in this chapter and Chapter 4 should be considered, to ensure that beneficial resources are able to maintain funding.

It is clear from the findings that Indigenous Hospital Liaisons play an important role in ensuring that Indigenous patients are comfortable in hospitals and are provided with the care and

resources they need. Improving health care outcomes for Indigenous people in Alberta will continue to be a long process, however Indigenous Hospital Liaisons will surely aid in this process and help ensure that, even if the process is slow, it is always moving forward.

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Appendix A: Interview Protocol for Indigenous Hospital Liaisons

Section 1: Personal Information

Q1:1: What is your name?

Q1:2: Are you Indigenous? Y/N

2a. Are you: First Nations/Métis/Inuit/non-Status

Q1:3: What community are you from/ do you have connections to?

Q1:4: How long have you been in this role as an Indigenous Hospital Liaison?

Q1:5: How did you become an Indigenous Hospital Liaison?

Prompt: Educational background? Employment background? Cultural background/experience?

Section 2: The Job

Q2:1: Can you tell me about your role as an Indigenous Hospital Liaison?

Prompt: Describe responsibilities, daily tasks, etc.

Q2:2: How is your contact with Indigenous patients initiated?

Q2:3: What services do you provide to patients?

3a. Family members?

3b. Staff?

3c. Others?

Q2:4: Have you been able to fulfil their requests? Y/N

4a. If no, why not? Please explain.

Q2:5: What are the most common topics/issues that you speak with patients about?

8a. Help patients with?

Q2:6: Are patients generally willing/unwilling/excited/standoffish?

6a. Please explain (**Prompt:** If patients are willing/excited, what do you think patients are hoping to gain from speaking to you about their experiences? If patients are standoffish/unsure, why do you think this is, and what could potentially be done to change this?)

Q2:7: What are the most rewarding aspects of your job?

Q2:8: What are the most challenging aspects of your job?

Q2:9: What do you think is unique about your role?

Q2:10: What surprised you most about your role when you first started?
Prompt: What were you expecting the job to be vs. what it actually is?

Section 3: Work Environment

Q3:1: What are common things that staff ask you to do?

1a. Who asks you (ie, which staff)?

1b. How do you feel about this?

Prompt: Reports suggest that your role is not clearly understood by other staff - do you think this is true? Does this create any challenges?

Q3:2: Can you give an example of something you have been asked to do that falls outside your role? Y/N

2a. Please explain.

2b. Does this happen frequently? Y/N

2c. What effect does this have your work (if any)?

Q3:3: What do you think could be done to improve the effectiveness of your role?

Prompt: Resources you need, training for staff, etc.

Q3:4: In your opinion, what are the major issues Indigenous people in Alberta encounter when accessing, or trying to access, health care?

4a. Are these issues prevalent at your site?

Q3:5: Do you think staff treat Indigenous patients are treated differently than other patients? Y/N

5a Please explain

5b Why do you think this is?

Q3:6: Have you ever witnessed problematic treatment of Indigenous patients by hospital staff?
Y/N

6a By other patients? Please explain

6b By hospital visitors? Please explain

Prompt: If you have not witnessed this treatment, what types of problematic treatment have Indigenous patients spoken to you about? Was it an individual that treated them this way? Or was it the health care system itself?

Q3:7: What are your thoughts on the Indigenous Awareness Training for AHS employees, or other cultural safety training that you have either heard about or taken part in?

Prompt: What parts are good? What parts need improvement?

Section 4: Creating Improvements

Q4:1: What do you think is needed to improve the experiences of Indigenous patients? Family members? (**Prompt:** Resources?)

Q4:2: Do you think that Alberta hospital staff should ask all patients if they identify as Indigenous? Y/N

2a. Why or why not?

Q4:3: What do you think your hospital is doing right in terms of serving Indigenous patients?

Q4:4: What could your hospital improve on to better serve Indigenous patients?

Q4:5: What is the most important thing that you would like others to know about the Indigenous Hospital Liaison role?

5a. Why is this important/why is this role needed?

Q4:6: This is the end of the interview. Is there anything you would like to address that I might have missed?

Prompt: Policy-wise? Awareness? Training?

Appendix B: Additional Interview Questions for the Rural Participant

Q2:6: Are there any unique challenges or obstacles due to the location of your site?

6a. Are there any ways that your role as an IHL is unique, compared to an IHL at an urban site?

Q4:1: What do you think is needed to improve the experiences of Indigenous patients? Family members? (**Prompt:** Resources?)

1a. Are there any additional improvements or resources needed, specifically for Indigenous patients at rural sites?

Appendix C: Modified Interview Protocol for Traditional Wellness Worker

Section 1: Personal Information

Q1:1: What is your name?

Q1:2: Are you Indigenous? Y/N

2a. Are you: First Nations/Métis/Inuit/non-Status

Q1:3: What community are you from/ do you have connections to?

Q1:4: What is your role(s) within Alberta Health Services? Specifically within hospital sites?

Q1:5: How long have you been in this role(s)?

Q1:5: How did you become a Traditional Wellness Worker?

Prompt: Educational background? Employment background? Cultural background/experience?

Section 2: The Job

Q2:1: Can you tell me about your role as a Traditional Wellness Worker?

Prompt: Describe responsibilities, daily tasks, etc.

Q2:2: How is your contact with Indigenous patients initiated?

Q2:3: What services do you provide to patients?

3a. Family members?

Q2:4: Have you been able to fulfil their requests? Y/N

4a. If no, why not? Please explain.

Q2:5: What are the most common topics/issues that you speak with patients about?

8a. Help patients with?

Q2:6: Are patients generally willing/unwilling/excited/standoffish?

6a. Please explain (**Prompt:** If patients are willing/excited, what do you think patients are hoping to gain from speaking to you about their experiences? If patients are standoffish/unsure, why do you think this is, and what could potentially be done to change this?)

Q2:7: What are the most rewarding aspects of your job?

Q2:8: What are the most challenging aspects of your job?

Q2:9: What do you think is unique about your role?

Q2:10: What surprised you most about your role when you first started?
Prompt: What were you expecting the job to be vs. what it actually is?

Section 3: Work Environment

Q3:1: What are common things that staff ask you to do?

1a. Who asks you (ie, which staff)?

1b. How do you feel about this?

Prompt: Reports suggest that your role is not clearly understood by other staff - do you think this is true? Does this create any challenges?

Q3:2: Can you give an example of something you have been asked to do that falls outside your role? Y/N

2a. Please explain.

2b. Does this happen frequently? Y/N

2c. What effect does this have your work (if any)?

Q3:3: What do you think could be done to improve the effectiveness of your role?

Prompt: Resources you need, training for staff, etc.

Q3:4: In your opinion, what are the major issues Indigenous people in Alberta encounter when accessing, or trying to access, health care?

4a. Are these issues prevalent at your site?

Q3:5: Do you think staff treat Indigenous patients are treated differently than other patients? Y/N

5a Please explain

5b Why do you think this is?

Q3:6: Have you ever witnessed problematic treatment of Indigenous patients by hospital staff?
Y/N

6a By other patients? Please explain

6b By hospital visitors? Please explain

Prompt: If you have not witnessed this treatment, what types of problematic treatment have Indigenous patients spoken to you about? Was it an individual that treated them this way? Or was it the health care system itself?

Q3:7: What are your thoughts on the Indigenous Awareness Training for AHS employees, or other cultural safety training that you have either heard about or taken part in?

Prompt: What parts are good? What parts need improvement?

Prompt: What are your thoughts on blanket exercises?

Section 4: Creating Improvements

Q4:1: What do you think is needed to improve the experiences of Indigenous patients? Family members? (**Prompt:** Resources?)

Q4:2: Do you think that Alberta hospital staff should ask all patients if they identify as Indigenous? Y/N

2a. Why or why not?

Q4:3: What do you think Alberta Health Services is doing right in terms of serving Indigenous patients?

Q4:4: What could Alberta Health Services improve on to better serve Indigenous patients?

Q4:5: What is the most important thing that you would like others to know about your role?

5a. Why is this important/why is this role needed?

Q4:6: This is the end of the interview. Is there anything you would like to address that I might have missed?

Prompt: Policy-wise? Awareness? Training?

Appendix D: Selected Insights from Participant 6 (Traditional Wellness Worker)

Highlighting Existing Resources

Weekly Indigenous Smudging Ceremonies (P.90)

The Traditional Wellness Worker that I was able to speak to facilitates weekly smudging ceremonies at several sites within Alberta Health Services. He shared with me how impactful smudging is for some patients. He described how patients will often come to the hospital in a frustrated state and have their mood greatly improved through smudging:

So I seem to get this a lot at [specific site], people come in really angry, and then I smudge with them and they're like "Hey, that was awesome!" Right? And I'm like, yeah, okay, great! So you can see those changes (Participant 6, 06/02/2020).

Mandatory Staff Training (P.90-92)

Staff members may also make a referral to a Traditional Wellness Worker without first consulting the patient. Again, staff may have good intentions when doing this, however this is not a truly culturally safe approach. Participant 6 explained:

I think whoever's making those referrals is kind of...well I wouldn't say it's rude, but I do think it's kind of ignorant. I think they're honestly trying to be helpful, but it's like, you know, you don't automatically call a chaplain for your non-Native patients, right? So, that's just cultural stereotyping I guess, within the hospital (Participant 6, 06/02/2020).

Unlike IHLs who provide cultural services as well as other services to patients, Traditional Wellness Workers specifically help patients with their cultural and spiritual needs. Referring a patient to a Traditional Wellness Worker without asking the patient means that the staff member assumed that the patient engages in traditional practices, which – as previously discussed – is not true of all Indigenous patients. Additionally, Traditional Wellness Workers visit patients at many sites within Alberta Health Services, meaning that they may have gone to a certain site specifically to see one patient. If the

patient never requested their services in the first place, this is a significant inconvenience to the worker, who often, like the IHLs, receives more referrals than he can get to.

Staff Initiative (P.93-95)

The Traditional Wellness Worker in this study shared his comments on staff members, which were generally positive. He commented that, “the vast majority of staff are pretty sensitive” (Participant 6, 06/02/2020), which is particularly encouraging as he provides services at many sites and therefore interacts with many different staff members. He noted that some sites have, “exceptional security” and that this can make a big difference in how Indigenous patients are treated. Previous studies have noted that security staff may be harsher with Indigenous patients (Browne et al. 2011). Dealing with patients in a respectful and fair way, even in difficult situations, is something that all security staff should aim for. This participant provides services at a safe injection site in Alberta, which often encounters more security issues than other sites. He noted that security at this site are exemplary and, “deal with the population professionally” instead of letting the stigma associated with the site influence their behaviour.

The Importance of Indigenous Hospital Liaisons (P.95-97)

The Traditional Wellness Worker recognized the value of the IHL role and enjoyed working with these individuals. When I asked this participant about existing resources within Alberta Health Services that benefited Indigenous patients he immediately responded, “having the liaisons, definitely.” (Participant 6, 06/02/2020).

Next Steps

Cultural Resources (P.97-98)

Participant 6 discussed how he had recently facilitated an additional smudge at an Alberta Health Services-managed long-term care facility. This site does not normally receive Traditional

Wellness Worker services, but staff members at the facility reached out and told him that several residents had specifically asked for him to visit. Seemingly by coincidence, several Indigenous patients had recently been discharged to this facility and had all previously attended smudging ceremonies at different hospitals, facilitated by this participant. He commented, “suddenly there were all these Natives there, and they’re all people I know.” (Participant 6, 06/02/2020). He continued:

They seem to be almost starting to build a community there. And not that it’s in my schedule by any means, but I’m going there once a month to smudge with them. And it seems to be really making their day when I show up there (Participant 6, 06/02/2020).

This highlights something that is often ignored in Indigenous health research, which is that health care sites are not limited to clinics and hospitals. Long-term care facilities are also health care sites and Indigenous patients in these facilities may benefit from cultural resources. This participant commented that he has spoken an IHL at one site and suggested that it might be beneficial to have more Indigenous patients discharged to the same facility. This would enable patients to build a community, as he suggested, and also enable him to provide smudging services for multiple patients at one site.⁴²

⁴² I have not seen similar suggestions in previous studies and think this is an inventive idea that could have significant benefits for patients. I personally did not find any studies that considered Indigenous peoples’ experiences in long-term care facilities in the existing literature, and these new insights shape the potential for future research into this area.