

**‘SHE IS IN THERE’: CONNECTING ACUTELY ILL INDIGENOUS CHILDREN
WITH PEDIATRIC CRITICAL CARE SPECIALISTS USING REMOTE PRESENCE
TECHNOLOGY**

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ABSTRACT

Indigenous children living in rural and remote Saskatchewan have limited access to pediatric specialty services. As such, they experience a high rate of medical transport out of their home communities. The Truth and Reconciliation Commission's Calls to Action prioritized access to health care that is culturally safe, and community directed. Remote presence technology (RPT), a novel form of telemedicine, seeks to overcome the barriers of distance and time to improve health care access. RPT allows for direct patient visualization, examination, and communication between the urban specialists and the local health care providers and family members. This study is part of a larger community-based participatory research (CBPR) project that evaluated RPT as a method of pediatric acute health care delivery. A single medical case from the larger CBPR project was used to explore the lived experience of a child, family, local and urban health care provider using RPT for a pediatric acute health care consultation. The exploration employed phenomenology guided by Indigenous world view. Findings revealed themes related to the value of building local capacity for pediatric specialized care and the related broader advantages of Indigenous children staying home for health care. Finally, the study revealed that indeed the technology created access, however its successful reception into the specialist-child interaction, is inextricably linked to the specialist that embodies it practicing cultural humility in order to provide culturally safe care.

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Dr. Mendez for his vision and advocacy to pioneer a solution that is patient-centered and has the potential to mitigate Saskatchewan and Canada's health care access challenges.

Veronica McKinney whose quiet strength, resilience and advocacy for all that is good, and kind is a marvel.

DEDICATION

I dedicate this thesis to my husband Simon and my daughters Sloane and Grier.

Simon, who makes me laugh every day and always has something new and interesting to teach me and our daughters. Sloane and Grier who bring me great joy and pride every day.

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LIST OF ACRONYMS

RPT: Remote Presence Technology

PICU: Pediatric Intensive Care unit

NP: Nurse Practitioner

LIST OF TERMS

Aboriginal: "... Aboriginal refers to the first inhabitants of Canada, and includes First Nations, Inuit, and Métis peoples. This term came into popular usage in Canadian contexts after 1982, when Section 35 of the Canadian Constitution defined the term as such" (UBC, 2009, p. 1).

First Nation: "...can refer to a band, a reserve-based community, or a larger tribal grouping and the status Indians who live in them" (UBC, 2009, p. 1). For example, Pelican Narrows First Nation.

First Nations: "A term used to describe Aboriginal peoples of Canada who are ethnically neither Métis nor Inuit. This term came into common usage in the 1970s and '80s and generally replaced the term 'Indian,' although unlike 'Indian,' the term 'First Nation' does not have a legal definition" (UBC, 2009, p. 1). Also referred to as "individuals legally recognized by the federal government under the Indian Act" (UBC, 2009, p. 1). The Indian Act was first passed in 1867 as a way of facilitating the administration of programs and facilitating the assimilation of Indian people into mainstream Canadian society (Waldram, Herring & Young, 2006).

Indigenous: "a term used to encompass Aboriginal peoples around the world. It is most frequently used in an international, transnational, or global context. This term came into wide usage during the 1970s when Aboriginal groups organized transnationally and pushed for greater presence in the United Nations (UN). In the UN, 'Indigenous' is used to refer broadly to peoples of long settlement and connection to specific lands who have been adversely affected by incursions by industrial economies, displacement, and settlement of their traditional territories by others" (UBC, 2009, p. 1).

Inuit: refer to Aboriginal peoples who have inhabited the Northern Regions of the Canada (Waldram, 2006). "Inuits are not considered Indians under Canadian law" (UBC, 2009, p. 1).

Métis: "...refers to a collective of cultures and ethnic identities that resulted from unions between Aboriginal and European people in what is now Canada. This term has general and specific uses, and the differences between them are often contentious. It is sometimes used as a general term to refer to people of mixed ancestry, whereas in a legal context, "Métis" refers to descendants of specific historic communities (UBC, 2019).

CHAPTER 1: INTRODUCTION

Health care access is a circumstance that impacts health outcomes (CSDH, 2008). Universal and timely access to pediatric specialty health care in Canada is a substantial challenge. Children living in remote locations are vulnerable because a lack of access to pediatric health care can result in poor health outcomes (CSDH, 2008). Timely access to health care services is a determinant of health and has been shown to be one of the most significant avenues of systemic racism that perpetuates the health care gap between Indigenous and non-Indigenous peoples (IHWG, 2016). Provision of pediatric specialty care to children living in remote locations routinely requires transporting them to regional or tertiary care hospitals that are located far from their home communities (Cameron et al., 2014). This colonized model of biomedical care utilizes a definition of specialty healthcare access as one that necessitates Indigenous children and families to leave their home communities. However, the desire of the Indigenous families and communities for access to specialty pediatric care comes at a cost and may be very different than assumed. There is a complexity involved in making the decision to transport an Indigenous child out of their home community that goes beyond medical health care decision making and compels us to contemplate Indigenous historical trauma and the Truth and Reconciliation Commission (TRC) Calls to Action (TRC, 2012a). In order to prioritize pediatric Indigenous health care parity, it is necessary to unravel the layers of health care access for Indigenous children and align them with the goals of Reconciliation.

Indigenous communities in Saskatchewan experience a lack of cultural safety in health systems, which contributes to poorer health outcomes for Indigenous populations compared to non-Indigenous populations (Loppie, Reading and Wean, 2009). Colonization causes dislocation across families, identities, language, cultural practices, and access to lands (Desapriya & Pike, 2006). These impacts, along with the intergenerational trauma of residential schools, result in an overrepresentation of Indigenous people seeking care in the health system, while simultaneously serving as a barrier to safe care within a colonized health system environment (Dell, Firestone, Smylie & Vaillancourt, 2015). A commitment to culturally safe care, prioritizing self-determination, and appreciating Indigenous historical trauma, lays the foundation necessary to guide a dialogue with the goal of finding solutions to enhance health care access for Indigenous children, without compromising decolonizing principles (TRC, 2015b).

Several decolonizing health care advantages are evident with the utilization of Remote Presence Technology (RPT) to enhance health care access to northern remote communities and

Indigenous children (TRC, 2015c). RPT is a form of telemedicine that creates the sense that a distant clinician/specialist is at the patient's side, while enabling clinical services to be provided remotely in real-time (Mendez & Van den Hof, 2013). Remote presence directly connects the local patient, family and health care team with the remote tertiary specialist. It allows the opportunity for the specialist, local team, patient and family to be partners in the care plan decision making. It promotes self-determination regarding the patient and family's health care priorities. Finally, it is a system that has the potential to support specialty health care access close to home and advocates for building local care expertise through direct clinical mentorship (Holt, Hansen, McKinney & Mendez, 2017).

Provision of culturally safe care involves acknowledging the power relationship between the patient and the care giver. Culturally safe care emphasizes the Indigenous patient as a partner in health care decision making (Dell et al., 2015). Moving care to an Indigenous patient's home community health center through RPT, enables the patient to be assessed at home and creates a direct opportunity for the patient to be an integrated part of the discussion related to health care planning. Consequently, RPT may empower the patient to be directly involved in decision-making, thereby promoting a patient caregiver interaction that is culturally safe. Direct visualization (through RPT) of a patient and their family in their home community may create an interaction that minimizes bias, blaming, and cognitive errors that can disrupt patient care giver trust and therapeutic decision making (Mendez, 2013).

Utilization of RPT is an illustration of an innovative health care solution that prioritizes a potential model of care that may mitigate colonized health care provision, promote reconciliation, with economic and historical justification to make health care policy amendments. RPT has the potential to optimize and narrow the Indigenous health care access gap (Holt, 2017). However, it requires the specialist inhabiting the device to engage remote Indigenous patients in a culturally humble manner, with an approach that respects the past, attempts to avoid aggravation of historical trauma, and aligns with the Calls to Action of the TRC (Tervalon & Murry-Garcia, 1998).

This study is part of a larger community-based participatory research project that is evaluating RPT as method of health care delivery with the quest to remove the barriers of distance and time in health care delivery in remote communities (Holt, 2017).

Utilizing qualitative research, this thesis uses a single medical case to examine the lived experiences of a child, family, local remote health care provider, and urban pediatric specialist provider. They were directly involved in health care delivered through RPT but also through the

traditional pathway, which involved transportation of the child to a regional and tertiary care center. Moreover, these experiences are considered through concepts of cultural safety and humility and related to the Calls to Action of the Truth and Reconciliation Commission (TRC, 2012a).

The Researcher

As a pediatric critical care and transport specialist (pediatric intensivist), I became interested in access to healthcare for children after starting a pediatric critical care practice in Saskatoon 11 years ago. Creating timely healthcare access is a challenge in Saskatchewan with its vast geography and high percentage of children living in remote communities. I sought to explore a way to overcome these challenges by studying the utility of remote presence technology as a way to deliver pediatric acute care in remote Saskatchewan communities. The quantitative prospective pilot project revealed the feasibility of delivering health care through a remote presence interface, however it did not examine the experiences of the remote local health providers or the patients and families on the receiving end. As the pediatric intensivist consulting through the RPT, I found myself forgetting I wasn't there in person, and grew connected with the health care teams and patients. I became fascinated with the story beyond the RPT biomedical consult and decided to pursue a qualitative study guided by phenomenology to explore the lived experience of the patient and care provider interaction.

Research Objectives

1. To reveal the experiences of an Indigenous patient and family who were recipients of pediatric specialized care, delivered both through the RPT device and through traditional care pathways, including transportation to regional and tertiary care centers.

What was the experience of the patient and their family when receiving pediatric specialized health care in their local community with and without the RPT device?

2. To reveal the experiences of the local health care professionals who participated in the delivery of pediatric specialized care that included RPT.

What was the experience of the health care providers (local generalist and urban pediatric specialist) who participated in the delivery of pediatric acute health care with and without the RPT device?

3. To relate these experiences to cultural safety, humility and Reconciliation in the health care system.

How do these experiences link to cultural safety and humility, as well as reconciliation in the health care system, as expressed in the TRC Calls to Action?

Organization of Thesis

This thesis is divided into five chapters. The introduction and research objectives comprise chapter one. In chapter two, the literature relating to health care equity; cultural humility and safety; Truth and Reconciliation and remote presence robotic technology are examined. The literature review explores the complexities of creating health care access for Indigenous children living in remote communities. RPT is discussed as a potential solution aligned with the relevant Calls to Action of the TRC. Chapter three provides the context for this study. In addition, it reviews the overarching Community Based Participatory Research (CBPR) approach guided by phenomenology as the key methodology informed by Indigenous world view. Chapter four summarizes the results and finally chapter five considers the experience with RPT revealed in this study, as it relates to health care equity, cultural humility and Truth and Reconciliation. Implications for practice and policy, as well as avenues for future research are suggested in concluding remarks.

CHAPTER 2: LITERATURE REVIEW

Achieving health equity and timely access to pediatric health care continues to challenge our socialized health care system in Canada. Access vulnerabilities translate to poor health outcomes (CSDH, 2008). Many of the health care challenges faced by remote Indigenous communities are not limited to access but rather are deep rooted by experiences of systemic racism and the quest to receive culturally safe and humble care (Dell et al., 2015). The TRC Calls to Action demand relevant health care actions that focus on culturally safe access to all levels of health care (TRC, 2012a). Remote presence technology (RPT) introduces an innovative opportunity to examine access in remote communities. This chapter explores literature relevant to health equity, cultural safety, cultural humility, the TRC Calls to Action and finally, the relevance of RPT as an option to narrow the gap in health care access for Indigenous communities.

Health Equity and Access to Health Care

There are numerous and varied definitions of health equity/inequity in the literature, but a widely accepted and cited definition originated from an article by Whitehead (1992). She defined health equity as "...all persons have fair opportunities to attain their full health potential, to the extent possible" (p. 430) Furthermore, she described health inequities as "...differences in health that are unnecessary and avoidable but in addition are unfair and unjust" (1992, p. 431). Braveman (2006) summarized a number of critiques around the idea that unfair and unjust were difficult to interpret and measure. Braveman (2006), proposed the following definition, "...health disparities/inequalities are potentially avoidable differences in health between groups of people who are more and less advantaged socially; these differences systematically place socially disadvantaged groups at further disadvantage on health" (p. 174). This definition was informed by Whitehead's (1992) original definition, which highlighted avoidable health disparities. Braveman (2006) went on to clarify that "...pursuing health equity means pursuing the elimination of such disparities/inequalities" (p. 173). Her definition has been favored because it does not require resolving the potentially subjective nature of the terms unjust and unfair. The World Health Organization (WHO) (CSDH, 2008), utilized Braveman's definition, affirming that when systemic differences in healthcare are deemed to be avoidable by reasonable action, health inequity can be averted. Cheng (2015, 965) further suggested that, "...although

disparities must be addressed on the population and policy level...clinicians have a critical role in promoting health equity” (Cheng et al., p. 961).

These definitions and interpretations of health equity are illustrated by data that revealed children less than 4 years of age living in low income countries experience mortality at a rate 20 times higher than high income countries (Gupta, de Wit & McKeown, 2007). In addition, remote communities have double the infant mortality rate, double the challenges to accessing health care, and five times the rate of teenage pregnancies (Braveman and Kumanyika, 2010). In Canada, Indigenous peoples experience ongoing health inequities that relate to living in remote communities, poverty, and a history of trauma that resulted in cultural genocide (Allan & Smylie, 2015). These vulnerabilities lead to complex barriers to health care and the consequence is suboptimal health care access for vulnerable children and their families (Allan & Smylie, 2015).

Creating health equity means promoting effective and directed health care for communities and populations and, eliminating healthcare disparities (Braveman, 2006). “Access to, and utilization of, health care is vital to good and equitable health” (CSDH, 2008, p. 8). The Commission on the Social Determinants of Health (2008) defined universal health coverage as “...access to the same rate of (good quality) services according to the needs and preferences, regardless of income level, social status, residency, and that people are empowered to use these services” (p. 8). There remain challenges in our Canadian and Saskatchewan health care system that perpetuate health care inequities, especially for Indigenous peoples. *Geography* and *jurisdictional* politics are among the largest.

Geography

Spagnuolo and colleagues, (Spagnuolo et al., 2019) in their research related to Obstructive Sleep Apnea (OSA), for example, showed that rural and remote living individuals don't receive timely diagnosis and access to specialized care. In Canada there is an association between where you live and accessibility of specialty services including specialty care. Clarke (2016) summarized findings from a national survey that examined barriers to specialized services in Canada. Canadians who reported poor perceived health also reported challenges accessing specialized services including specialist care, non-emergency surgery and selected diagnostics tests. Barriers to specialized healthcare services can lead to delays in diagnosis, timely intervention and result in poor health care outcomes (Clarke, 2016).

Many Indigenous communities in Canada are remote and the available health services frequently lack the infrastructure for comprehensive interventions to achieve optimal outcomes. Achieving access for Indigenous children living in remote northern communities often results in a high rate of pediatric medical transports outside of their home community (Oosterveer & Young, 2015). This is suboptimal for the acutely ill Indigenous child, because there are challenges related to timeliness of care provision when the prerequisite for care is leaving their home community. Pediatric acute care is a specialty service not readily available to remote northern Indigenous communities (Oosterveer & Young, 2015), yet in many of the northern remote Indigenous communities more than fifty percent of the population are less than seventeen years of age (Stats Canada, 2016). In addition, a Canadian report released in 2017 revealed that Indigenous children aged 0-9, and 10-19 were 1.8 and 3.8 times respectively, more likely than their non-Indigenous counterparts to be hospitalized in a regional or tertiary care facility (Guèvremont, Carrière, Bougie, & Kohen, 2017). Accordingly, Indigenous children are frequently leaving their home communities for health care. Furthermore, Saskatchewan has the highest percentage of children aged <14 years of any other province in Canada (19.6%); 42% of Saskatchewan Indigenous children are <19 years and over 30% of these children live in rural/remote/reserve communities (Stats Canada, 2016). Saskatchewan geography is vast, and rural and remote communities are difficult to access by air, particularly with precarious weather. This leaves children in road ambulance services travelling long distances and many hours before specialized health care is received.

Jurisdictional Barriers

There remains a significant gap in health outcomes for Indigenous as compared to non-Indigenous Canadians, in part as a consequence of lack of access to services due to jurisdictional disputes between the provincial and federal governments. This has led to the adoption of Jordon's principle (a child-first policy), following the death of a child in hospital while waiting for resolution of funding disputes regarding home health services. The principle, and related policy, mandates that no First Nations child should wait for health care services (acute, chronic or home), while jurisdictional responsibility is being evaluated. However good in principle, this policy continues to leave out groups of Indigenous children that suffer the consequences of the jurisdictional health care funding barriers (Gunnarson, 2018). The child and family presented in this study are from a First Nations Community. Braveman (2006) asserts that health equity results from the removal of avoidable systemic differences in health. In Saskatchewan and

Canada, timely health care access, delayed because of provincial and federal jurisdictional policy, is an example of an avoidable systemic difference in health for Indigenous children. Caring for Indigenous children in their home community is a mechanism to remove this avoidable jurisdictional barrier to health care access. The Truth and Reconciliation Commission identified achieving health equity as a key factor in moving toward Reconciliation, with mutual respect necessitating direct community and family involvement in decision making (TRC, 2012a). Addressing the avoidable contingencies of health care access both geographical and financial, may begin to address this challenging but critical endeavor.

Beyond the contemporary geographical and jurisdictional policy health care access barriers to avoidable health equity, however there are additional considerations for Indigenous children that are located in residential school and TB sanatorium history as well as ongoing child welfare policy. For many Indigenous communities, injustices in these areas have resulted in distrust and fear when their children must leave home.

Truth and Reconciliation

The Canadian Truth and Reconciliation Commission (TRC, 2012a) released a report on the impact of residential schools on First Nations peoples in 2015. 94 Calls to Action were presented to achieve Reconciliation. The TRC identified the Calls to Action as "...a rare second chance to seize a lost opportunity for Reconciliation" (TRC, 2012a, p. 1).

They Came for Our Children (TRC, 2012d) begins with an 1883 quotation from the Public Works Minister of Canada at the time, Hector Langevin, that stated "In order to educate the children properly we must separate them from their families. Some people say that this is hard but if we want to civilize them, we must do that" (title page). The federal government instituted Indian Residential Schools (IRS) to assimilate Indigenous children into a colonial Canada (TRC, 2012d). Children were removed from their homes and separated from their parents, families, and Elders under the guise of education. Indigenous children were stripped of their culture and deprived of basic sanitation, nutrition, and support for healthy child development (Mosby, 2013). Many Indigenous children did not see their parents for years, were neglected, and suffered from emotional, physical, and sexual abuse. The Indigenous child who left home for residential school in many cases never returned. Their mortality rate was shockingly high (Potvin, 2015). Instead of enhanced education, the IRS system resulted in consequences that included inter-generational health disparity and cultural genocide (Kasper,

2014). Attendance at an IRS has since been shown to independently predict poor health outcomes for Indigenous people through the life course (Pahwa et al., 2015).

Historically, when Indigenous children left home, there were unexpected and traumatic outcomes (TRC, 2015b). The high mortality rate of Indigenous children in the 19th and 20th century sanitariums for tuberculosis treatment, as well as the 11,000 children who were forcibly placed in the child welfare system during the sixties scoop (Reading & Nowgesic, 2002) were additional traumas that span generations, resulting in visceral fear of an Indigenous child leaving his/her home community (Lux, 2010). However, these egregious realities are not limited to the past, as there are more Indigenous children in foster care now than occurred during the entire sixties scoop period (Blackstock, 2011).

In a subsequent summary by the TRC (TRC, 2015b) the process of Reconciliation is described as inspiring both Aboriginal and non-Aboriginal peoples to be involved in Canadian societal transformation where we live together on lands that we share in "...dignity, peace and prosperity" (TRC, 2015b, p. 8). Furthermore, the Commission explains that, reconciliation in Canada begins with all Canadians educating themselves regarding Canadian Indigenous history and the deep roots of these conflicts. The lack of knowledge has ongoing consequences for Indigenous peoples including resolving issues related to treaty agreements, jurisdictional challenges with federal government policies, and the basic pervasive racism that perpetuates the distrust between Indigenous and non-Indigenous peoples (TRC 2015b). Ongoing jurisdictional challenges are illustrated by Jordon's principle elaborated earlier (see page 9). The TRC summary emphasizes that understanding the truth is critical for reconciliation (TRC, 2015b).

Kirkness & Barnhardt (2001) present the four Rs (Respect, Relevance, Reciprocity, Responsibility) as important to approach university education regarding First Nations peoples. Many of these same principles appear in the supplement, *What We Have Learned: Principles of Truth and Reconciliation* (TRC, 2015c), created by the TRC Commissioners. These principles are summarized in Table 2.1 (see page 14). Within the principles document, the Commissioners identified several Rs that underpin the changes to Canadian society that they are looking for including "...all Canadians, as Treaty peoples share the responsibility for establishing mutually respectful relationships" (TRC, 2015c, p. 4). The Commissioners go on to discuss the importance of relationships with each-other, the natural world and the earth. They state that "...reciprocity and mutual respect will sustain survival, ...the kind of healing and survival that is needed in moving forward from the residential schools" (TRC, 2015c, p. 123). A critical part of this process involves repairing damaged trust by making apologies, providing individual and

collective reparations, and following through with concrete actions that demonstrate real societal change. Establishing respectful relationships requires the revitalization of Indigenous law and legal traditions. Finally, in order to inform the reconciliation process, Canadians need to educate themselves regarding the traditional First Nations, Inuit, and Métis' approaches to resolving conflict, repairing harm, and restoring relationships (TRC, 2015c).

TABLE 2.1 GUIDING PRINCIPLES OF RECONCILIATION (TRC, 2015c, p. 3)

Guiding Principles for Reconciliation
The <i>United Nations Declaration on the Rights of Indigenous Peoples</i> is the framework for reconciliation at all levels and across all sectors of Canadian society.
First Nations, Inuit, and Métis peoples, as the original peoples of this country and as self-determining peoples, have Treaty, constitutional, and human rights that must be recognized and respected.
Reconciliation is a process of healing of relationships that requires public truth sharing, apology, and commemoration that acknowledge and redress past harms.
Reconciliation requires constructive action on addressing the ongoing legacies of colonialism that have had destructive impacts on Aboriginal peoples' education, cultures and languages, health, child welfare, the administration of justice, and economic opportunities and prosperity.
Reconciliation must create a more equitable and inclusive society by closing the gaps in social, health, and economic outcomes that exist between Aboriginal and non-Aboriginal Canadians.
All Canadians, as Treaty peoples, share responsibility for establishing and maintaining mutually respectful relationships.
The perspectives and understandings of Aboriginal Elders and Traditional Knowledge Keepers of the ethics, concepts, and practices of reconciliation are vital to long-term reconciliation.
Supporting Aboriginal peoples' cultural revitalization and integrating Indigenous knowledge systems, oral histories, laws, protocols, and connections to the land into the reconciliation process are essential.
Reconciliation requires political will, joint leadership, trust building, accountability, and transparency, as well as a substantial investment of resources.
Reconciliation requires sustained public education and dialogue, including youth engagement, about the history and legacy of residential schools, Treaties, and Aboriginal rights, as well as the historical and contemporary contributions of Aboriginal peoples to Canadian society.

Despite the closure of the last residential school in 1996, and the publication of the TRC's Calls to Action, inequities experienced by Indigenous peoples of Canada remain pervasive. The current health care gap between Indigenous and non-Indigenous Canadians is unfair and unjust. Infant mortality among Indigenous children range from 1.7 to over 4 times the non-Indigenous rate. Inuit homelands experienced a rate of 188.0 deaths per 100,000 person-years, with suicide being 6-11 times more likely. First Nations youth living on reserve aged 10-25 years have six times the rate of suicide compared to non-First Nations. Alcohol related deaths are 6 times more likely in Aboriginal peoples and drug induced deaths three times more likely. Finally, Indigenous peoples over 45 years have nearly double the rate of diabetes (TRC, 2015b).

Within the TRC report there were seven Calls to Action specific to health (Table 2.2), including recommendations for meaningful change related to jurisdictional disputes between provincial and federal governments for health care services. In addition, enhanced access to basic health care was identified as a priority. Respect for the context of not only Indigenous history and community challenges, but also community strengths and assets, may allow for transformative, supportive, self-directed health care change (TRC, 2012a). RPT technology may be one solution that meets the directives of improved access to health care with capacity to respect context.

**TABLE 2.2 HEALTH CARE RELATED TRC CALLS TO ACTION (TRC, 2012a,
p. 2-3)**

Health Care Related TRC Calls to Action
18. We call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.
19. We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.
20. In order to address the jurisdictional disputes concerning Aboriginal people who do not reside on reserves, we call upon the federal government to recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal peoples.
21. We call upon the federal government to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority.
22. We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.
23. We call upon all levels of government to: <ul style="list-style-type: none"> i Increase the number of Aboriginal professionals working in the health-care field. ii Ensure the retention of Aboriginal health-care providers in Aboriginal communities. iii Provide cultural competency training for all healthcare professionals.
24. We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism.

Cultural Safety, Cultural Humility and Self Determination

The purpose and approach of this study are rooted in concepts of health equity, cultural safety, and cultural humility (CAH, 2013). Pervasive in these concepts is the recognition that systemic racism continues to create a barrier between Indigenous peoples and their health care providers (Leyland et al., 2016). Literature on these concepts has informed the development of the research objectives/questions (see page 4) and underpins the study’s interpretive framework. These concepts locate the observed health disparities between Indigenous and non-Indigenous communities and the impacts of both historical and contemporary colonization.

In Canada, Indigenous peoples experience systemic racism that is often revealed with multiple intentional or unintentional assumptions based on patient diagnosis and related health

behaviors. Consequently, the necessary trust and mutual respect required to achieve a successful health care experience and outcomes is compromised (Leyland, 2016).

The Truth and Reconciliation Commission Report stated:

For over a century, the central goals of Canadian Aboriginal policies were to eliminate Aboriginal governments; ignore Aboriginal rights; terminate the Treaties and, through a process of assimilation, cause Aboriginal peoples to cease to exist as distinct legal, social, cultural, religious and racial entities in Canada (TRC, 2015b, p. 1).

This has led to societal beliefs of Indigenous peoples as an inferior social group resulting in provision of only basic resources and the avoidable consequence of inequities. The result is systemic racism against Indigenous peoples in Canada (Leyland, 2016).

Several examples related to the health of Indigenous peoples in Canada illustrate systemic racism, including the historical and persistent effects of colonial policies regarding mandatory residential schools; tuberculosis treatment via sanatoriums; and child welfare legislation. Furthermore, Indigenous children are currently the predominant population in social services' care. Additional contemporary examples of Indigenous peoples suffering systemic racism within the health system include, chronic food and housing insecurity compared to their non-Indigenous counterparts (Allan, 2015); geographically and systemically worse access to specialized health care services (Cameron, 2014); racism in emergency rooms; (Puxley, 2013; Dell, 2016); and the most recent and devastating experience of Indigenous women and forced sterilization in Canada (Virdi, 2018).

A commitment to the self-education and provision of culturally safe care has been proposed as a modifiable action to resist systemic racism. Culturally safe care has been defined as "...an outcome of care that enables those who receive services to define safe care" (Cameron et al., 2014, p. E6). Cameron et al. (2014) goes on to describe culturally safe care for Indigenous peoples as care that integrates the relevant historical and political issues related to their health. Cultural safety results from working with Indigenous peoples and communities in the way that they define safe care. Therefore, training clinicians to provide culturally safe care through culturally competency may not be sufficient. It is not necessarily cultural practices that define cultural safety in health care, but rather the identification of the social, economic, and political situation of Indigenous peoples in Canada and how those factors impact their health (Walker, Kelly & St. Pierre, 2009). Self-critique and becoming aware of one's own attitudes toward

diverse populations, such as Indigenous peoples, allows self-identification of pre-existing intentional or unintentional systemic racism. This has been described as the process of becoming culturally humble, which is ultimately a prerequisite for cultural safety and avoidance of systemic racism (Tervalon, 1998).

Medical delivery, guided by cultural humility, emphasizes a commitment to enduring self-reflection on the part of the health professionals to address power and culture imbalances inherent in the patient-physician interaction. Tervalon (1998) described cultural humility as a mutually beneficial partnership that advocates for communities and individuals. This concept transcends how care is delivered (through technology or in person), as it requires a critical approach that is delivered by an individual fostering trust, mutual respect, and a partnership in medical decision making. Despite having a strong theoretical foundation in the literature, there is a lack of knowledge translation about the impacts of culturally safe health care provision received in the local communities (Dell, 2015).

Remote Presence Technology (RPT)

RPT is a mobile form of telemedicine that creates the sense that a distant clinician is at the patients' side, while enabling clinical services to be provided virtually in real time (Kristofferson, Coradeschi & Loutfi, 2013). Previous studies have demonstrated that RPT allowed successful triaging, treatment and decreased the need for transfer of rural adult patients to a tertiary intensive care unit (Murray, Oritz & Cubin, 2014). Furthermore, RPT showed reduced medical air transports out of a Canadian arctic village (Mendez, Jong, Keayes-White & Turner, 2013). In pediatrics, telemedicine allowed successful triaging and treatment of disaster victims (Burke et al., 2012) and has been shown to be reliable for the evaluation of critically ill children, aide in determination of disposition, and enhance pediatric transport effectiveness (Heath, Salerno & Hopkins, 2009). Telemedicine has been associated with a reduction in pediatric transfers from remote communities (Cifuentes, Romero & Godoy, 2017) and increased regionalization to non-tertiary centers (Harvey, Yeager, Cramer, Wheeler & McSwain, 2017). Moreover, telemedicine devices are reliable in evaluating critically ill children and enhance pediatric transport effectiveness (Siew, McCarthy & Agarwal, 2016).

We recently completed a pilot study looking at triaging pediatric acute care transports with RPT telemedicine device (Holt, Sari, Hansen, & Bradshaw, 2017). The RP-7i remote presence robot (InTouch Health Inc., Santa Barbara, CA) is a United States Food and Drug Administration class II medical device approved for application in acute patient care. The RP-7i

can be controlled by any Wi-Fi connected computer with the appropriate software. The robot emulates the size of an adult with a height of 165 cm and has a mobile flat screen monitor that displays an image of the clinical operator's face (Figure 2.2).

FIGURE 2.1: RP-7i REMOTE PRESENCE ROBOTIC DEVICE



Clinicians can independently undock the robot from its wall-mounted charger and drive it to the patient at approximately 3 km/hr. The RP-7i's high definition cameras, microphones, speakers, and peripheral digital devices (stethoscope, dermatoscope, otoscope) can also be controlled by the clinician. These remote features enable direct visualization, examination, and diagnosis of the patient, as well as communication with local healthcare professionals and family

members. Usually with a nurse's assistance, the RP-7i also allows real-time auscultation and facilitates mentoring in basic procedures such as intravenous access (Mendez, 2013).

The recruitment site was a northern Saskatchewan nursing station in a First Nation community that provides temporary acute care but does not admit pediatric acutely ill patients. The clinic has varying degrees of pediatric medical expertise on site at any given time (RN, Nurse Practitioner, Family Physician). Prior to the RPT pilot study, 100% of acutely ill children were transported to a regional or tertiary pediatric center if the local care provider called for transport, requesting a higher level of care. Following the RPT deployment, there was a significant decrease in the number of patients (especially respiratory illnesses) requiring transport out of their home communities (43%). Health care follow-up visits at 24 hrs. and 14 days after the initial acute presentation showed that the virtual triage decision-making was safe and sustainable (Holt, 2017).

Measurable advantages were revealed through the original pilot project, including decreased need for expensive medical transports, increased availability of the single provincial specialized pediatric transport team, increased local care capacity, and decompression of the often overcapacity tertiary and regional pediatric centers. (Holt, 2017) However, what was uncertain from the pilot was the perspectives of the providers, patients, and families who received care and had decision making regarding transfer accomplished through a virtual device. Previous studies have explored participant perspectives in telemedicine delivery models. A pediatric primary care system showed providers appreciated timely access to specialized acute care consultations for their patients. (McConnochie et al., 2010) Ray et al. (2017) published a study that explored family perspectives on telemedicine for pediatric subspecialty care. Their findings revealed that families saw potential value of using telemedicine to replace in-person subspecialty visits, however they were more enthusiastic about using telemedicine to complement rather than replace in-person visits.

A recent pediatric telemedicine survey revealed that families of pediatric patients with different clinical problems are keen to embark in telemedicine programs, independently from severity of disease or chronicity, and of distance from the hospital (Russo et al., 2017). However, a family member of an adult patient in a California regional ICU recently released a statement of disappointment that the palliative nature of the man's disease was released to him by video conference. The telemedicine physician and program defended the process, stating that this conversation was a follow-up and their telemedicine program is not meant to replace critical

conversations, but rather complement them with provision of additional accessible expertise that would not normally be available without travel during critical illness (Associated Press, 2019).

To our knowledge, family and provider perspectives regarding RPT utilization for triaging acutely ill Indigenous children has not been explored. The pilot revealed clinical and economic benefits; however, family and provider perspectives are also essential to explore as part of the overall clinical experience. We are interested in how the utilization of the RPT technology affects perceptions related to pediatric health care access and health equity interpreted within the context of the Calls to Action of TRC and concepts of cultural safety and humility. This exploration is critical prior to expansion of the pediatric northern RPT program to unravel the complicated layers of pediatric health care delivery with Indigenous children, a marginalized and traumatized group historically with associated significant health care gaps.

In summary, as the impacts of remote presence pediatric health care delivery are uncovered through this project, further contemplation may materialize regarding health equity, the TRC Calls to Action and, the intersecting concepts of cultural safety and humility as they pertain to pediatric medical transports and triaging acutely ill Indigenous children with robotic technology.

CHAPTER 3: CONTEXT AND METHODOLOGY

This chapter begins by providing context for the medical case that is under study, including an overview of the preexisting medical processes that were required for health providers working in remote Indigenous communities to access acute pediatric specialty care. Phenomenology and its relevance as a methodology when exploring lived experience with Indigenous peoples will be outlined. Finally, utilization of a single medical case will serve as the architecture for our exploration of the lived experience of the RPT acute pediatric specialty interaction. The chapter concludes with a description of methods, including data collection, analysis, and ethical considerations.

Context

Pediatric patients with acute medical pathology frequently leave general practitioners hesitant to make definitive assessments and initiate lifesaving therapies (Heath, Salerno, Hopkins, Hertzig & Caputo, 2009). Rural hospitals and clinics may lack appropriate pediatric equipment or support personnel and may not have immediate access to subspecialty pediatric consultations. Life-threatening illnesses in children are events that occur with low frequency but have high potential for morbidity and mortality. With infrequent opportunities for experience in dealing with these emergencies, rural providers may have a greater need for urgent assistance from specialists in pediatric critical care medicine (Athey, Dean, Ball, 2001).

The First Nation in this study is located in northwest Saskatchewan, 386.2 km away from the closest regional pediatric health center (5 h 5min by road) and 525.9 km away from the closest Tertiary care center (6 h 27 min by road). It has a population of 1,913 (Statistics Canada, 2011) and is only accessed by road 3/4 of the calendar year. There is an airport, but because it is a dirt runway with no consistent night-time lighting, it can only be accessed by plane during the day and in the winter and/or dry summer months. Prior to the deployment of the RPT device, when an acutely ill child presented to this community clinic, there was a complex process that the local team had to navigate in order to create access for their patients. This process was formidable in that it often required the local health care team to take multiple steps prior to accessing pediatric acute specialty care advice. This process had the potential to compromise timely initiation of care and led to a culture of care whereby when they finally proceeded through these complexities, the request would be made for transfer to regional or tertiary care. In part

this was due to the fear related to lack of direct pediatric health care access advice if a child's clinical status deteriorated quickly.

In addition, the pediatric specialized clinical advice received by the local team occurred through a telephone conversation. There are limitations to the telephone process related to medical phone advice, especially within the context of Indigenous pediatric health care. Perhaps the most important of these is that the telephone discussion pertaining to the child's health care plan excludes the parents, family, and Elders (Dell, 2015). This was described by a local physician as similar to receiving information through an interpreter. The local provider phones the specialist, the specialist gives advice and makes the decision regarding transfer. That entire conversation culminates in plan that is relayed back to the family. The family or Elder does not have the opportunity to ask follow-up questions or seek clarification. Furthermore, it eliminates the opportunity for follow-up questions with the specialist regarding residual fears or concerns related to their child's acute medical status.

In addition, diagnostic discordance has been documented between referring remote local care providers and the pediatric specialists in receiving tertiary care centers when using the telephone call process. Therefore, the tendency of receiving pediatric critical care specialists is to advise medical transport out of the local center to tertiary care where the patient can be directly assessed (Philpot, Day, Marchande & Gorelick, 2008).

The consequence for acutely ill children from the Saskatchewan First Nation in this study was an approximate 400 to 600-kilometer journey to the nearest regional or tertiary hospital respectively. This local reality, which broadly emulates the majority of northern medical clinics in Saskatchewan, perpetuates a system where specialized pediatric health care access does not move to the sick child, but rather requires the sick child to be mobilized to create access. This care very much mirrors a colonial system whereby Indigenous children are forced to leave their home community to receive access to health care, education, or welfare custody. We were compelled to reevaluate pediatric acute care delivery for northern Indigenous children and develop an innovative solution to narrow this health care access gap, while aligning the solution with the Calls to Action from the Truth and Reconciliation Commission. This became a priority for me, as access to health care is a basic right as well as a social determinant of health. Dr. McKinney, the medical director for Northern Medical Services, as well as an Indigenous Family Physician had been on a similar quest, looking for creative solutions to overcome barriers to healthcare access in northern Saskatchewan when she discovered RPT and Dr. Ivar Mendez. Dr. Mendez pioneered RPT in Canada, and first evaluated its utility in a small Inuit community in

Nain (Mendez, 2013). His move to Saskatchewan and early collaboration with Dr. McKinney led to a community-driven deployment of the RPT to the First Nation in this study. They began communicating with this First Nation two years prior to deploying the robot as a response to a call from community members for improved access to specialty health care, particularly for acutely ill children. It was near this time that I met Dr. McKinney and Dr. Mendez, given our aligned healthcare access priorities, and my relevant pediatric critical care and transport subspecialty. Together we further developed a Community Based Participatory Research (CBPR) pilot project. The objective of the pilot was to assess the feasibility of caring for acutely ill children through the RPT and triaging their capacity to stay home for ongoing care via the RPT or discuss transfer with the patient/family and local health providers. This pilot uncovered many compelling observations both measurable (elaborated on page 19) and unmeasurable (eg. impact on the family; fears associated with transfer) (Holt, 2017). The original goal was to utilize the technology to increase pediatric acute care access and refine pediatric critical care transport triaging to prevent unnecessary transfers and travel for Indigenous children. However, the findings culminated in unexpected learnings, community engagement, and the development of profound humility by the pediatric intensive care specialists, of whom I am one. The humility came from the direct observation (virtually) and appreciation of the pre-existing lack of standard pediatric health care access and what I see now as my own ignorance to have had the impression that transporting the majority of acutely ill Indigenous children was the safest approach. That delivery model lacked creativity, reflected a poor understanding of local northern clinic resource realities, and did not reveal an understanding of Indigenous historical inter-generational traumas.

Mothers and fathers of sick Indigenous children wanted the same as mothers and fathers of children living in Saskatoon visiting the Pediatric Emergency Department. That is, they wanted their child to feel better, be given a diagnosis, receive a management plan, and follow-up recommendations. Ideally, they would like to be able to take their children home. Unfortunately, in certain scenarios, when a pediatric specialist diagnosis and recommendations were needed, the children from this remote First Nation did not have the option of staying home and families understood the inevitable necessity of travel in order to have their child receive specialized pediatric healthcare.

It is impossible to duplicate pediatric specialized programs throughout Indigenous remote communities, however, given the dire implications of removal of Indigenous children from their home communities and the layered fear associated, we were motivated to explore RPT as potential solution to create access and potentially reduce transports, for Indigenous children in

this First Nation through virtual specialists' visits. The First Nation community in this study had already embraced the concept of RPT over the two-year period with community member involvement and had identified sick children as the number one priority.

During the year-long pilot study, relationships developed between the local providers and the tertiary care pediatric intensivists, as well as with certain children (and their families). The pediatric intensivists gradually became familiar with the local equipment, medications, investigations that were available and were able to make suggestions regarding local enhancements for necessary diagnostics and therapeutics. The experience working with the pediatric intensivists allowed local providers to become familiar with management algorithms in a systematic way for common pediatric acute care presentations. One of the most rewarding and unexpected outcomes of the original pilot was the realization by the pediatric intensivist that the calls from local providers had slowed down after 11 months, and therefore, the pilot recruitment had slowed down too. When the local team was asked by the intensivist why they hadn't called for help lately, the response was "...we are getting pretty good at acute care pediatrics now... may not need your help anymore...hahahah."

I quickly realized that there were untapped layers of experience to capture and I felt compelled as a pediatric specialist and clinical epidemiology student, to take a phenomenological journey through the lived experience of remote pediatric acute care with and without the RPT with the providers and the families.

Methodology

Community Based Participatory Research. This CBPR study of which the current study is one component, occurred between 2013-2016 as a pilot projection in a remote northern Saskatchewan First Nation community.

Community Based Participatory Research (CBPR) prioritizes the community in the development of a partnership between the research team and the community in question. The principles of health education and community capacity-building underlie the fundamental utility for CBPR as a research approach with the aim of public health promotion and social justice (Minkler, 2004). The topic for CBPR can be initiated by the outside researcher if the topic is supported by the community as a high priority, and if a community liaison is an integral part of the methodology and decision-making (Minkler & Wallerstein, 2003).

The associated research study evaluated the feasibility of using an RPT device to deliver pediatric acute care. The primary outcome examined the number of transported children out of their home community to receive health care at a regional or tertiary care center. The findings can be summarized as follows: 14 out of 38 (37%) children required transport, whereas all of the children in the control group were transported ($p < 0.0001$). In short, children who did not receive care and triaging with the RPT device were transported out of their home community to a regional or tertiary care hospital 100% of the time. Six of 14 (43%) transported children were triaged to a nearby regional hospital, while all of the children in the control group went directly to tertiary care without being regionalized closer to home ($p < 0.0001$). All of the children who remained at the clinic stayed < 24 h and were matched to children in the control group who stayed 4.9 days in tertiary care (Royal University Hospital) ($p < 0.001$). The pilot project concluded that RPT reduced the need for specialized pediatric inter-facility transport, while enabling regionalization when appropriate. The authors maintained that the results may have implications for the broader implementation of RPT, while reducing costs to the healthcare system. The quantitative results were compelling and demonstrated RPT as a feasible and effective mode of pediatric health care delivery (Holt, 2017). However, unexplored qualitative inquiries endured after the study's completion.

The experience of the children, families and health care providers when receiving and delivering health through the RPT device had yet to be explored. During a knowledge translation presentation to the community, there was an inquiry about the family and health care provider perspectives with regard to receiving/delivering children's specialized healthcare in their home community. This was identified by the First Nation community group as a critical and relevant knowledge gap given the inter-generational trauma related to a history of Indigenous children having to leave their home communities. CBPR is community directed, and following the quantitative pilot study there was direction given by the community to obtain a greater understanding of the family and health care provider perspectives regarding RPT. This led to the current study.

Ontological and Epistemological Location. The qualitative exploration is guided by phenomenology informed by Indigenous world view (Ellerby, 2006) and the principles of TRC (TRC, 2015c). Indigenous world view aligns well with the phenomenology approach because it seeks to elicit the lived experience from individual participant's shared experiences or stories (Burnette, Sanders, Butcher & Salois, 2008). Furthermore, this methodological approach creates

the space to draw out concepts and thematic relationships underpinned by cultural safety, humility, health equity and the TRC Calls to Action as relevant to RPT health care delivery. The CBPR pilot study identified pediatric acute health care as a priority and consequently the study evaluated the RPT as a potential health care access solution with the focus and methods being biomedical. The current study builds from the pilot, to explore the lived experience of an RPT pediatric medical case, with the child patient, her Mom (with Dad present) and the local health care provider, and me as the remote presence pediatric intensivist involved in this medical case.

Phenomenology. The term phenomenology was first advanced by the philosopher Husserl (Dowling, 2007), identified in writings by Kant in 1765, and further described by Hegel as an entity which derives knowledge from consciousness (Moustakas, 1994). Lived experience entails the natural experience of people prior to abstraction or reflection (van Manen, 1990). Research utilizing phenomenology methodology pursues the nature of lived experience through the chronicle of people. (Burnette, Sanders, Butcher & Salois, 2012) Phenomenology seeks to understand what an experience is like and in this study it is the experience of delivering and receiving acute pediatric health care with Indigenous children with and without the support of a virtual pediatric specialist through a RPT. Phenomenology seeks to evaluate lived experience through open ended research questions using in depth narrative interviews (Caelli, 2000). Although phenomenology honors individual stories it also reveals universal experiences across people (Dowling, 2007).

Indigenous Phenomenology. Phenomenological research among Indigenous peoples has revealed congruences between phenomenological methodologies and Indigenous oral traditions (Kovach, 2009). Oral tradition integrates concepts relating to circularity, holism and connectedness and exemplifies Indigenous peoples core values. Utilizing a linear format-often inherent in the traditional scientific process does not embody the research lens necessary to illustrate Indigenous world views (Ellerby, 2006). Oral tradition is a primary operando within the culture of the ways Indigenous peoples as a means to share information across the lifespan (Wilson, 2008). Therefore, the utility of phenomenology for exploration of the lived experience of an Indigenous child and family receiving health care in a unique way through the RPT can be seen as a culturally safe methodology (Smith, 1999).

Medical Case Report. In biomedical research a case report approach is used for presenting a rare and discreet medical case. The methodology utilizes a descriptive approach (Sayre, Toklu, Ye, Mazza & Yale, 2017). The terminology of case report is often interchanged with the term case study. However, case study is traditionally used within the social sciences and the differences between them have implications for the approach to inquiry and presentation of the case. McEwen (1996) clarifies case reports as “descriptions of practice without research methodology” (p. 3). The intention of a case report is to describe a phenomenon or event but generally not to evaluate cause and effect.

McEwen (1996) goes on to describe a case study as an “...empirical inquiry that investigates phenomenon in real-life context especially when boundaries between the phenomenon and the context are not clearly evident” (p. 3). Although our study used a single medical case as would be used in a case report, the medical case served as the structure through which to develop our research inquiry. In this way this study represents more than a case report but does not claim to be a case study. Case report inquiry relates the experience of RPT within the context of a pediatric acute care consult and links that experience to the benefits or risks of this medical delivery model.

The medical case is presented here using pseudonyms, except for myself. The medical case is centered around Grace, a 4-year-old girl who was first seen through the RPT at two years of age but had also received medical care without the RPT prior to its deployment. Grace’s mother, Vanessa, and a local nurse practitioner, Rachel, were also part of the medical case, and therefore, this inquiry. Finally, although I am the researcher for this study, I also was the intensivist who cared for Grace during her RPT interaction, as well as previously without the RPT. The University of Saskatchewan Research Ethics Board and Saskatchewan Health Authority granted approval for the study. I approached Vanessa via phone to see if she, her husband, and Grace would participate. The nurse practitioner in this experimental study for Grace’s care, was also approached by phone call. All individuals involved in the case gave verbal consent over the phone and written consent in person prior to participation in this study. I had travelled to their First Nation community prior to and following the original CBPR pilot project. I offered to come back to conduct the qualitative interviews. However, they both had a pre-arranged trip planned to Saskatoon, therefore we met in person in my office.

Data Collection and Analysis

Interviews were carried out with 4-year-old (Grace) and her mother (Vanessa) as well as a local nurse practitioner (Rachel). All research participants consented to audio recording during the interview as well as their photos being presented within this thesis.

The semi-structured interviews consisted of open-ended questions. Interview data was collected from three participants via audio recording in my office. In addition to audio recording, I took hand written notes and added detail immediately following with field notes (with permission from the participants). I spent 2.5 hours with Vanessa and Grace, between Grace’s interview and drawings and Vanessa’s interview. Grace’s Dad was present during both interviews, however he requested to be an observer only. I met with Rachel for one hour and 45 minutes during which semi structured interview questions were audio-recorded. This was followed by a less formal discussion for which I made notes. I produced a written narrative account of my experience as the pediatric specialist in this case and during the RPT experience.

Table 3.1 outlines the introduction script and interview questions that guided the conversation for each participant.

TABLE 3.1 INTRODUCTION SCRIPT AND SEMI-STRUCTURED INTERVIEW QUESTIONS

	Child	Parent/Family	Remote Local Health Provider
Introduction script	When we first saw you, you were really sick and I took care of you in Saskatoon. Then I saw you again at home with the robot. Can we chat a little bit about that today?	When I first met your child I saw her as a paediatric specialist through the robot. Today I am here as a researcher interested in exploring your experience receiving health care delivered with and without the robot.	We have been working together with the robot to take care of sick children My role with you until now has been as the as a paediatric specialist giving medical support through the robot. Today I am here as a researcher interested in exploring your experience delivering pediatric health care with and without the robot
Semi-structured interview questions	<ol style="list-style-type: none"> 1. Do you remember the robot? 2. Can you draw the robot? 3. Can you draw the day that I came to visit you with the robot? 4. How did you feel? 	<ol style="list-style-type: none"> 1. How did you feel when you saw the robot? 2. What did you like about it? What didn't you like about it? 3. Can you compare the experience receiving care from the robot to a time that your daughter didn't get care from the robot? Follow-up: how involved did you feel in the decision making of your child? 	<ol style="list-style-type: none"> 1. When you first saw the robot how did you feel about using the robot to connect with sub specialists to assist with care and advice? 2. How did you feel when you used it? 3. How did it impact your opinion regarding transferring paediatric patients out of the community for health care?

Following interview transcription, the transcripts and notes were analyzed through inductive and deductive thematic analysis (Fereday & Muir-Cochrane), beginning first with the inductive approach. The literature review (page 6-20) informed the deductive coding. For example, I created codes relevant to the TRC and residential schools. This resulted in multiple codes pertaining to the child, family and health care provider's notions about their experience with the technology and pediatric care delivery. All codes were subsequently organized into themes that we further organized into larger categories of meaning.

The next chapter covers the results.

CHAPTER 4: RESULTS

The results are first presented through the story of each participant, including my story as the researcher, but also as the inhabitant pediatric specialist of an RPT device. This presentation format is consistent with Indigenous informed phenomenology, holding storytelling as a key pathway for knowledge dissemination (Ellerby, 2006). The stories are presented as a hybrid of medical case narrative and individual voice (followed by the thematic findings). The presentation of experience begins with the child around whom the case is centered. Her Mom's (Vanessa) story is presented next, signifying the importance of family in Indigenous world view. The hybrid case report-experimental narrative concludes with the remote and local health care provider's stories: (Nurse Practitioner Rachel) and then urban specialist (myself). The second part of the results chapter offers thematic presentation of findings. Providing the results using these two approaches in this sequence invites the reader to first immerse themselves in the case and its story, before navigating through my interpretation.

Participant's Story Narratives

Grace. Grace was 20 months old when she first met the RPT (inhabited by Dr. Holt). She was born healthy but in her first year and a half of life she was seen at the clinic many times and required transfers out of her remote First Nation community. The first time she was seen by Dr. Holt through the RPRT she had pneumonia and needed a diagnosis and treatment plan including whether or not she would require transfer to Prince Albert or Saskatoon for ongoing care. She was so unwell during the first consultation she didn't seem to notice that Dr. Holt was a robot. Grace's Mom and Dad spoke directly to Dr. Holt and they decided they would try treatment at home with close follow-up. She was followed up on the next day, and her symptoms were improving. During the follow-up appointment Grace was curious about the robot but not scared. In total, Grace was seen with the robot on three occasions over 15 months. Two of the clinical assessments with the robot resulted in a care plan that involved her staying home for ongoing treatment, and one resulted in her being transferred to Saskatoon for ongoing care. Without the robot she would have been transferred all three times based on comparisons with the pilot control group (Holt, 2017).

She was four years old when interviewed about her experience. Grace described the robot as blue and white, which is remarkable since it has a blue/grey color and she had not been seen by the robot in over a year at the time of the interview. While discussing her memories of

the robot we asked her to draw how she was feeling about her experience. She drew a rainbow (Figure 4.1). When asked if she was afraid of the robot, she said no. When asked whether the doctor in person was better or on the robot, she said it was the same. Her answers and demeanor throughout the interview were relaxed and calm. Following the interview, we went for a walk to visit the robot in person. She hugged the robot and giggled in the same way as when she hugged the robot during a previous clinical follow-up visit (Figure 4.2).

4.1: Rainbow drawn by child participant: Grace



Figure 4.2: Participant Grace with the RPRT device



Vanessa (Grace’s Mom). Vanessa is a First Nations woman, a wife, and mother of four, with many responsibilities to keep her family happy and healthy. When Grace became sick during her first year of life, Vanessa had to leave their home, their extended family, and their other children to stay with Grace in Prince Albert and Saskatoon for days. This was hard for her and her family, but she would do anything to be sure Grace received the care she needed. She said it was not an option to let her be transferred on her own to a hospital without being there with her to make sure she got better and came home.

When Vanessa was first introduced to Dr. Holt, as the inhabitant of the RPT, she was skeptical, but during that visit as she observed directly the local nurse practitioner and Dr. Holt working together, she could see and hear the specialty consultation that was happening. When Dr. Holt told her that Grace had pneumonia but that it was appropriate to provide a trial of treatment at home before transferring out, Vanessa was delighted she could stay at home but

asked if Dr. Holt was sure that was the best decision. A follow-up plan was organized that made Vanessa feel more comfortable and during the days following that initial assessment she watched Grace's respiratory status improve and she marveled at the possibility that she may not always have to leave when Grace gets sick.

Before the robot came it was hard when, for Grace to get the right diagnosis and if she doesn't get the right diagnosis, she usually gets medevac'd to either to Prince Albert or to Saskatoon. And where we stay a week or two weeks, away from our home community.

When Vanessa described the experience with and without the robot, she revealed that although she had initial apprehension, this was quickly followed with relief because her daughter received her diagnosis and specialized care quickly. Vanessa went on to compare in person pediatric assessment requiring transport out of her home community versus robotic assessment.

Like I didn't like it the first time I said eh, I don't think this is going to work. But after we went through that, the interview with you like everything was fine. Like I was relieved that you were there for my daughter. We'd be on the plane, coming to Prince Albert or Saskatoon. That's what I like about it now. I don't have to leave the kids and find a babysitter and you know we are gone for at least nine to ten days when she gets sick. That's why I really appreciate the robot now. Like we need more in our communities, like not only in _____ but everywhere else.

Vanessa felt the technology would be important for Elder healthcare too. "...It's helping kids, ...helping doesn't have to be just the kids but could be the Elders too ...I like it." During the RPT follow-up appointment we discussed the reasons why Grace may be getting recurrent pneumonia, did some investigations and then a referral was made to a chronic pediatric lung specialist, who would also go on to see Grace through the RPT device. Vanessa said she felt like she was involved in Grace's care, especially regarding the transfers out of her community when facilitated with the RPT. Vanessa highlighted the empowerment she felt to be involved in the direct virtual discussion and have a clear role in determining the next course of action for her child's care. "...like we didn't have a choice when she was getting sent out" Vanessa described

Dr. Holt as "... in there" and felt a presence, albeit virtual. Vanessa and her husband laughed and said they think Grace loves the RPT.

It helped my daughter to get the right diagnosis instead of us traveling that seven-hour drive for her to get to a hospital for better care ...and just leaving my other family behind like a week at a time.

Vanessa shared what she heard from the community about the robot for delivery of medical specialist care. "...Uh, probably a mix, a mix I think you know...some people say that's not right, you'd be better to see somebody face-to-face, but it is almost face-to-face, I mean you are in there." Vanessa and her husband now feel RPT opens up the possibility of staying home for health care. However, on one occasion when Vanessa brought Grace in acutely to be seen through the RPT, Dr. Holt told her that Grace needed to come to Saskatoon's PICU. Vanessa said "...I trusted Dr. Holt and knew that if Grace could stay home, she would have recommended that."

She went on to say finish by saying "...when I met Dr. Holt in person, I felt like I kind of already knew her."

Vanessa says Grace has been doing really well in the last six months. Vanessa began working outside of the home and Grace's access to pediatric specialty care has been steadfast and her health optimized. She said she and her husband are spending a lot of time with extended family and their new grand baby.

Rachel (Nurse Practitioner). Rachel Johnson is non-Indigenous and started working as a Nurse Practitioner (NP) in this community in 2014. She had worked in several northern communities and was extremely interested in advocacy for Indigenous People's health care. She had already experienced several occasions where children were acutely and critically ill and she had to jump through numerous hoops to even get advice via fax. She had observed the RPT device in the staff room and said she daydreamed that it could be the answer to the pediatric patient's access to acute health care challenges. The RPT had arrived in the community during the initial phase of the CBPR process following robust discussion regarding the utility of this mobile Telehealth RPT unit as a potential way to improve health care access to the community. The community members were keen on trialing the technology as access was such a challenge,

however, there was a period of time that passed before they made the decision that the acute or critically ill children were to be prioritized. When Rachel heard the community had identified acute care pediatrics as a group in need and that a CBPR pilot intervention study would be initiated with a pediatric specialist, she was relieved as she too recognized children as an extremely vulnerable cohort with regard to timely health care access. In her interview she described a case that she will never forget.

A baby who was critically ill had to go to P.A on a treacherous road after that same baby was sent back home from another regional hospital without a diagnosis or intervention.’ The baby died on the way to P.A and I vowed to advocate for children and their families and get some pediatric training and expertise and be a champion for health care for northern remote living children.

She became one of the primary NPs working with the pediatric specialists and Dr. Holt to care for acutely ill children in the community through the RPT. She described having the pediatric specialist there virtually as a “...game changer.” She elaborated explaining that she sees the specialists as a mentor who gave her a sense of confidence in her assessment to accept, adjust or refine her diagnosis and help develop a management plan. The virtual relationship also supported the validation of her knowledge and skills with the families that often wonder if her recommendations were sound. She described advancing her own personal pediatric skills and knowledge. “...gave me a lot of confidence, helped develop my skills, increased my capacity to take care of children in the community...it was like having direct mentorship... it was a relief to have the support.” She began diagnosing and managing frequent problems in which she had been mentored without even needing to call the pediatric specialist for advice via the RPT. She said she could feel their clinic formally ‘building capacity’ to manage sick children at home. She went on to describe how that feeling resulted in a transformation in their delivery of pediatric care.

Rachel also described a reverse mentorship situation with the RPT in that the local health care provider became the educator for the virtual pediatric specialist regarding regional care and cultural realities. She felt she had an important advocacy role for the patient to receive culturally safe care and to support the specialist’s growth of cultural humility.

Rachel went on to become the local pediatric expert honing her pediatric skills with continuing medical education, accessing direct support through RPT when necessary, and

running a pediatric clinic locally. She organized subspecialty pediatric talks for the local clinic staff and created access stability in the community for sick children. Ultimately, she handed over her role as pediatric specialist to a colleague who she had mentored and also who received mentoring from the pediatric intensivists through RPT. Rachel is now a coordinator for the provincial RPT program and is advocating for expanded utilization of RPT in Saskatchewan and broader access for more communities to more subspecialty services.

Rachel reflected further on her desire to provide safe and quality care for children in their community, pointing out that while there were many positive aspects of RPT, it also produced challenges. The most significant is that the RPT resulted in a new workload. "...at times it can increase workload...it will be important to look at the resources we have, and the acuity levels to see how we can manage that better..." Rachel was referring to the increased workload related to the human resource time it takes to convalesce an unwell child in their clinic as the treatment strategies take effect. The alternative is immediately transferring the patient out and the need for ongoing monitoring and reassessment for additional intervention is eliminated. However, she said "...even with the increased workload it is critical that we prioritize this capacity building endeavor."

Rachel also described the linkage she sees between the virtual care with the RPT device and health equity and the Truth and Reconciliation (TRC) Calls to Action. She connected both to the Canada Health Act, which guarantees universality, accessibility and comprehensive health care. She explained that Elders have described health care as an issue of "institutionalization ...everybody gets sent out, sent away." Rachel was keenly aware of residential schools' impact and pointed out that while the last school closed in 1996, she worries that this history is echoed in pediatric transport for healthcare. She went on to describe the disruption that occurs when community members are sent away.

Particularly when a child is transferred out to a regional or tertiary care center, and a parent must accompany that child. The vast majority of people would prefer to stay in the community. They often have family obligations, Elder parents and siblings and so sending out is very disruptive to the family unit.

Her interview responses revealed the access gap for Indigenous communities but then highlighted the robot as a potential solution or "...game changer." Her dialogue re-affirmed local health care access as critical to avoid community and family disruption. Rachel also recounted

the healthcare experiences community members have shared when they have had to leave their home community for regional or tertiary care.

When people are in the health care system at the tertiary centers or in the regional health care system, they feel, like people who are marginalized, still experience discrimination and inequitable care. And that's demonstrated time and time and time again. And so being able to let people stay in their communities, not sending out and sort of breaking part of that cycle is, I think going to be quite profound. And having the local health care workers who they know and trust, many of whom are from the communities themselves, so speak the language, know the history, having them provide the care with the support from the specialist really has the potential of, of, breaking that cycle of colonialism. One of the big things is you are going to be working with the local providers and the patient is going to be receiving their care in their local environment as opposed to going to major institutions and trying to navigate that system.

Dr. Tanya Holt (Pediatric Intensivist). I am a mother, non-Indigenous, I have been trained as a nurse, and I am currently a pediatrician with a subspecialty is pediatric critical care and transport medicine. In my job as the division head of our single pediatric intensive care unit/pediatric critical care transport (PICU) team in the province, I quickly recognized health care access as a critical challenge particularly in northern Indigenous communities given Saskatchewan's geographic vastness, the paucity of human and transport assets available, the variable health care resources across the province and with a high percentage of children living in northern rural/remote communities (Statistics Canada, 2016). My initial thought was to increase community access to the pediatric transport team and tertiary care admission, however we only had one pediatric transport team, limited tertiary care beds and growing volumes. I began lobbying for more tertiary care resources including greater transport assets. What I didn't know then that I have been so privileged to learn through this research is that those additional assets would never be able to truly close the healthcare gap for Indigenous children living in remote communities. This was because I was using my own definition of what pediatric healthcare access meant. The meaning of access needed to come from the communities and the families and needed to be facilitated in a culturally safe way.

As the inhabitant doctor of the RPT device, I had a tremendous experience providing subspecialty support and advice to the local healthcare providers, while virtually meeting families with acutely ill children in a remote community, just like the one in this study.

However, as I worked through the 13-month pilot project I became more and more aware and concerned about my ignorance. The more families I met the more struggle I had- not regarding how to treat the child's status asthmaticus, septic shock or status epilepticus but rather I feared being disingenuous. I previously assumed that all families with sick children wanted to come to tertiary care where pediatric specialists practiced. I soon realized that indeed they wanted expertise for their children but maybe not at the expense of leaving home. I wanted to contribute to a solution but grew weary and worried that I would make assumptions about matters that I could never pretend to fully understand. This was a delicate balance- contribution but respecting the past, the context and the culture and never overstepping. I was immediately humbled by the local health care access realities and resources, as well as to the importance of provision of care that was culturally respectful and prioritized the family's input regarding decision making for their child's care plan about transfer versus not.

I first met Grace while she was in the Pediatric intensive Care Unit (PICU) in Saskatoon when Grace was acutely ill with pneumonia. Several months later I saw Grace in her home community through the RPT during another acute respiratory illness. For the first time on a remote consult I could actually see the concern in the family's eyes and hear the vulnerability in their words through the RPT. This was something I had been ignorant to previously, when receiving the remote consult by telephone and having a fellow health care provider translate the patient's clinical symptoms. While using the robot, I found myself forgetting I wasn't there in person and became completely engaged in communicating my observations, diagnosis and treatment plan with both the local health provider and the family. This was so different from previous telephone consults in which I was unable to discuss the care plans with the family directly. I remember Vanessa's face (Grace's mom) when I told her that we could safely manage Grace at home based on her exam, her vital signs and how she looked when she was breathing. She was delighted. I had made the assumption that she would want Grace to come to Saskatoon, where there were pediatric specialists to continue her management. I remember her response, which was "oh what a relief we get to stay home."

I began to respect the complexity and implications involved in making the decision to transport an Indigenous child out of their home community, which compelled me to educate myself. I began reading the TRC document and literature around cultural safety and humility. I became respectful of the responsibility that I had in inhabiting the RPT to virtually provide pediatric subspecialty care. The responsibility was deeper-rooted than medical triaging decision-making. Countless families had the same response as Vanessa, but one Mom's

response I remember very clearly. I asked her why she was so relieved to be able to stay home for care and she responded, "...when my child leaves, I am worried she will never come home."

I felt an enhanced sense of accountability to the families and local team. Further, as my experience increased with virtual care through the RPT it became extremely apparent that utilizing the telephone to take pediatric acute care consults was suboptimal. Creating timely access to acute care for Grace and other children cannot be dependent on simply transportation (even with a specialty team) but rather requires an integrated model of care delivery that prioritizes direct visualization, examination and communication with the family and local team for every consultation. I ended up seeing Grace several times during our 15-month pilot project. On one of the occasions, I decided that she needed to come to the PICU. I was able to explain the reasons why she had to come to Grace's Mom and Dad and began definitive management with the local team prior to the pediatric transport team arriving. I remember Vanessa saying, "...I trust you Dr. Holt, ...whatever you decide." I realized that despite the fact that I had only met Grace once in person, we had developed a relationship that involved trust.

Grace gave me and my medical student a hug on the RPT one day during a follow-up visit. I remember feeling like I was experiencing something extraordinary and a non-negotiable change in the way we deliver medical care for our remote living patients. We have a deep responsibility to Reconciliation, in particular for Indigenous children, who have historically experienced repeated traumas. One of the ways the RPT can respond to the TRC Calls to Action for Reconciliation is to overcome the barriers of distance and time to health care access for Indigenous children and their families. This became my quest during the overarching CBPR pilot project, however my direct but virtual experiences with the patients and families generated personal realizations beyond optimizing and creating timely access to medical care. I had a new feeling of accountability regarding the immense responsibility it was to triage an Indigenous child to either stay home or be transported out of their home community for medical care. My clinical lens evolved throughout the CBPR process and became informed by the principles of Reconciliation after reading the TRC report and its supplements as well as the document, *They came for our Children* (TRC, 2012d).

The local health care team blossomed and was growing their pediatric knowledge and skills throughout the pilot project because they were managing acutely ill children when possible with direct mentorship. Recruitment for the pilot study dwindled after a year in this remote community. When questioning one of the nurse practitioners about the drop in the number of acute calls her response was "...we are getting really good at acute care pediatrics."

This was a brilliant and rewarding moment. The culture of pediatric acute care prior to deploying the RPT was to transfer out children who were acutely ill because there is an understanding that children's illnesses can be subtle and evolve quickly. Transportation modes and availability were precarious in ___ therefore getting them 'out' while they could, was the priority. Having direct support for diagnosis and decision-making regarding management and disposition triaging gave the local team the confidence they needed to keep some acutely ill children locally for care. In addition, communicating directly with the families during the RPT consultations provided the opportunity for family education regarding their child's illness. Topics included early warning signs for symptom progression and how to recognize these warning signs. I recall one consultation for a different child when I entered the patient room with the RPT device, and the NP had been called away to another patient. I asked the Mother to help me with the stethoscope on the back of the robot. I also asked if she wanted to listen to her child's lungs with me, so she knew how they sounded when they were sick. She was happy and excited and after the NP arrived in the room the Mom said with a chuckle '...we are finished the exam.' I saw that same Mother several weeks later and she reported that she recognized the symptoms early because she knew what to look for. This was profound because the RPT visit had allowed this Mother to receive education and grow knowledge regarding her child's disease and feel empowered to confidently bring her in for assessment when necessary. Finally communicating directly with the family allowed the opportunity to discuss transport decision making and include the family as a partner in the decision-making choice.

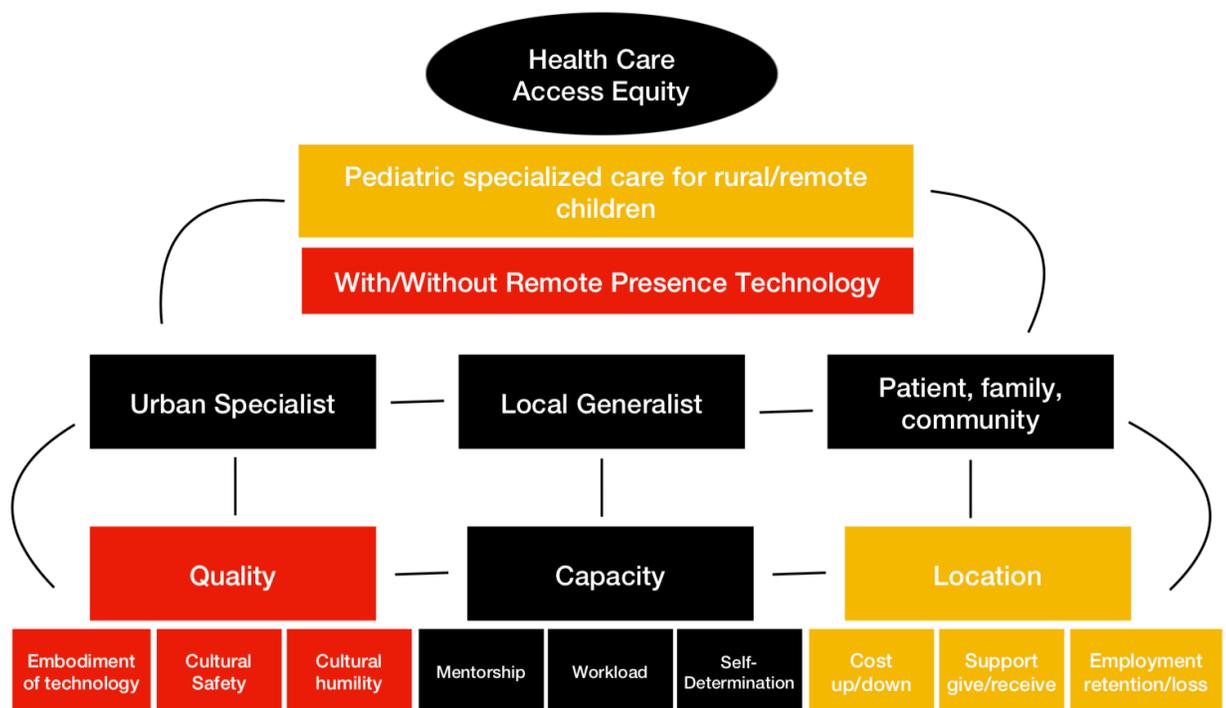
The initial call from the community was for enhanced access to pediatric acute care support. This CBPR pilot resulted in improved access to subspecialty pediatric care and mentoring for local care providers to maintain the response to that call. Furthermore, the call created the opportunity to find an innovative solution to address access, a TRC Call to Action.

As I progressed through the CPBR, including the journey of developing cultural humility, my perspective regarding RPT and its benefits shifted. RPT is about creating the opportunity to develop relationships that are difficult to develop with a phone call. It is those relationships that allow the connection, trust and sharing that is vital in any quality care interaction whether in person or through the RPT. I felt privileged to have virtual discussions with families, Elders, the children and the local care providers. I feel that my relationship with Grace, her family and many others through the RPT captured the reconciliation process.

Results of Thematic Analysis

This next section of the results chapter summarizes the results through locating key moments of these stories into themes. These are depicted in Figure 4.3 in terms of linkages I see between them, with some elaboration beyond the individual narratives in the discussion that follows.

FIGURE 4.3 THEMATIC RESULTS



Underpinning the experience shared in all four stories, and permeating the themes is the necessity of accessible and timely pediatric health care that is close to home.

A critical and related theme is the essence of the pediatric specialized care as being a *quality* experience whether virtual or in person. Grace’s interview and observations from her drawings revealed feelings of safety, happiness and a lack of distinction between the robot and human doctor. This lack of distinction or virtual embodiment of the RPT is a theme that repeats throughout the other stories as well. All the participants, including myself, as the virtual pediatric specialist reflected the sense of ‘being in there.’ The knowledge procured from the

interviews revealed an impression of positive embodiment of the RPT that occurred, that I feel reflect the elements of respect, humility and cultural safety as integral to the care experience.

Capacity is another theme that was evident in the stories of the health care provider and includes mentorship, workload, and self-determination. Virtual pediatric specialist to local health care provider mentorship resulted in learnings through direct observation and mutual respect and appreciation of each other's roles. As the local provider's pediatric knowledge and skills enhanced, the ability to manage acutely ill children increased, and this translated into a newly acquired workload. Although there were associated challenges with this newly acquired work load the impression was that the nature of the change in work load paradigm, contributed to an evolution in the local health care practice autonomy, culminating in familial trust and newly developed local self-determination for delivery of pediatric acute care. The NP, Rachel, emphasized how the RPT allowed the extended family to be involved with family members for support or decision making. She went on to highlight this advantage as promoting family-centered care which is a priority in Indigenous world view (Dell, 2015). The family also received education related to their child's illness and as such became empowered to recognize when to access health care. In addition, the direct discussion regarding transport options with the local team and family allowed the family to be a part of a clinically appropriate choice regarding their child's care or transport disposition. Vanessa (Grace's Mom) marveled at her involvement in decision making regarding medical transfer with the introduction of the RPT. She highlighted the fact that for the first time she felt she had 'choice' related to her child's transfer.

Finally, *Location* is an important theme as it impacts health care and family costs; availability of support networks and access to employment. Vanessa highlighted some of the benefits of staying home for local pediatric health care now possible through the RPT. She didn't have to leave her other children with alternate childcare, she could maintain her job and income, and finally she values the presence of extended family support, in particular her Elders.

The experience and implications of family leaving home for health care were practical, featuring leaving family, employment, and finding childcare as major stressors. However, in addition to the practical challenges of leaving home, the stories identified conflicting fears related to transfer or not. These fears were deep rooted from previous experiences of having to leave home and underpinned by Indigenous historical context as discussed in Chapter 2. Family members expressed a desire for *quality* care but also care close to home when appropriate.

Both Rachel and Tanya described a critical interest in prioritizing the TRC Calls to Action in daily medical delivery, and furthermore emphasized that inhabiting the RPT is a profound responsibility and one that requires a genuine commitment to the journey of cultural humility.

Summary

The thematic analysis identifies the characteristic features of a pediatric acute care delivery model that may successfully integrate RPT as a solution that promotes health care access equity for remote First Nations and Métis communities in Saskatchewan. As figure 4.3 illustrates, the themes articulate in a circular relationship between the family and community, local and urban pediatric specialist linked through quality, capacity and location. RPT integration for health care to improve pediatric acute health care relies on a process of building capacity in communities through direct access to mentorship, reassessment of resources to accommodate the work load and ensuring the community members are supportive of the model of care. The positive embodiment of the RPT as identified by the development of a successful relationship with a patient and family, supports the utility of RPT as a potential remote health care access solution consistent with the TRC Calls to Action. This embodiment, however, is not solely a technology success, but rather also requires the clinician inhabiting it to practice culturally safe care. The results of this study are compelling and leave a sense of moral and ethical responsibility to expand this pediatric delivery model throughout the province. However, as the discussion will reveal, the infrastructure of the current medical system makes this solution a challenge in many ways. These barriers and future implications for this technology as a culturally safe solution for health care access equity will be explored in the next chapter.

CHAPTER 5: DISCUSSION

The CBPR pilot project that informed the current study demonstrated the economic and clinical feasibility of RPT as an innovative solution to narrow the pediatric health care access gap for Indigenous children. At its conclusion it became clear that inhabiting the RPT and delivering pediatric specialty health care to Indigenous families in their home communities requires more than sharing expertise and supporting decision making regarding pediatric acute care and transport options. Issues of health equity and access bridge the goals of the original pilot project and the focus of this thesis, which is the human experience of RPT. I was determined to unravel the relationships and lived experience of receiving and delivering acute pediatric specialized health care virtually, using an RPT device. The four stories reveal rich experiences that point to the value of RPT beyond economic and clinical feasibility to equally compelling imperatives around the social determinants of health and health care Calls to Action in the TRC. The following discussion is organized around this study's thematic findings: quality pediatric health care close to home; building pediatric health care capacity in northern remote communities; and the cultural humility necessary to 'embody' the RPT in a culturally safe way.

Building Indigenous Pediatric Healthcare Capacity

Access is one of the seven TRC Calls to Action related to health care (TRC, 2012a). Providing pediatric health care in rural Canada is a substantial challenge. The paucity of health care providers with expertise in pediatrics necessitates the routine transportation of children over great distances to regional or tertiary care facilities. Indigenous children are particularly vulnerable as many live in remote communities without specialty trained pediatric providers. Access to health care is a determinant of health and remains one of the major reasons for the health outcome gap between Indigenous and non-Indigenous Canadians today (Cameron, 2014). Although nearly 50% of the rural and remote population of Indigenous communities are under the age of 17 (Statistics Canada, 2016), they are typically void of comprehensive and local pediatric programming. Furthermore, with Canada's geographical vastness, providing effective and timely access to acute pediatric consultation is difficult (Philpot et al., 2008). There are often multiple steps for rural/remote referring clinicians when attempting to access specialty advice. This barrier can result in a hesitancy for rural clinicians to make definitive assessments and initiate optimal therapies, often resulting in activation of unnecessary medical transports to avoid diagnostic discrepancies (Hansen, Beer & Vallance, 2017). Within our current delivery model,

Indigenous children, regardless of their condition or criticality, experience a high rate of medical transports and routinely leave home. The system is rooted in western biomedical and a colonized approach, as discussions pertaining to the Indigenous child's management often exclude the parents, family, and community.

Understanding the importance of self-determination to Indigenous communities is paramount to creating decolonized pediatric health care delivery. A critical step involves seeking understanding regarding how Indigenous communities define pediatric health care access (CAG, 2013). Pediatric intensivists cannot reside in all remote northern communities, therefore, RPT delivery of health care may be a model that creates virtual presence in every community when needed. This system has the opportunity to empower Indigenous self-determination, decolonization, and reconciliation.

My experience with RPT shows that it affords tertiary specialists like me the opportunity to better understand the remote health center and the local realities to not only provide timely and improved virtual clinical expertise, but also advocate for acquisition of standardized medical resourcing. Learnings and mentorship occur for both the tertiary specialist and the local generalist. Local providers contribute to building pediatric acute care capacity through their conscientious engagement and learnings during RPT interactions with the tertiary specialist.

The culture of pediatric acute care in remote communities has been to transfer out early for fear of the patient destabilizing and unable to access care (Philpot, 2008). This culture has led to fewer interventions being performed in the community and acutely ill children being transferred long distances without goal directed therapies that are lifesaving. Consequently, remote communities are often not resourced to manage acute pediatric problems and deaths have occurred while patients were en route for care (Philpot, 2008). The NP involved in this study described preexisting barriers to access and residual care provider fear after an infant died while waiting for specialized pediatric care advice and disposition. This culture of care that has evolved in this First Nation and many other northern communities perpetuates transporting children long distance to receive pediatric acute health care access. It is contradicted by the deep-rooted community fears attached to the meaning of a child leaving home for healthcare as it relates to Indigenous historical context and the inter-generational trauma that took place (TRC, 2015b).

In this study, the local health care provider embraced the opportunity to be involved in managing an acutely ill child with the virtual support of a pediatric intensive care specialist. As a consequence, the culture of care for acutely ill children shifted and the local capacity grew for pediatric acute care. Bidirectional learnings occurred resulting in a deeply acquired mutual respect and humility between the local NP and the pediatric intensivists. For me as the intensivist, it was humility regarding the local resources and equipment; humility regarding the local clinic's capacity to manage acute care pediatrics; humility in my assumption that all pediatric patients should be quickly transferred away from home for healthcare; and humility regarding Indigenous history and the guiding principles of the TRC.

With regard to the specialist perspective, whereas in the past a quick telephone call would result in a potentially uninformed decision to transfer to regional or tertiary care, this process was identified as irresponsible following the results of the original RPT CBPR pilot that showed the majority of children presented could be treated locally (Holt, 2017). Furthermore, telephone-based consultations and transfers cannot be justified with evidence that there is an 11.5 % diagnostic discordance rate between the impressions of a local generalist provider and a pediatric specialist (Philpot, 2008). Early on in preparation for our pilot project, Dr. Mendez, Dr. McKinney and myself, travelled to Sacramento where they showcased a multi-regional high functioning telemedicine stroke program. Within their program they had a 'no curbside medicine policy' meaning that with the advent of telehealth solutions it is unconscionable to make decisions about patient care over the phone at the side of a road (Heath, 2009).

Although RPT helps refine transport decision making it does result in a greater time commitment for all healthcare personal involved, including the remote specialist, who could not just answer or dial the telephone, but rather had to log on to a laptop and drive the RPT device to the patient for evaluation. However, the capacity for local care was not limited to the local health providers. The families became empowered to participate in their child's health care management by being in the room during the assessment, directly answering questions from the specialist, and receiving direct education from the pediatric intensivist regarding future warning signs and symptoms. In addition, it allowed them to become a partner in the decision-making regarding transfer or not.

With our understanding regarding the complicated implications of transferring an Indigenous pediatric patient out of their community and given the understood effectiveness of telemedicine to deliver quality care, the extra time it takes for virtual assessment and informed decision-making makes RPT and telehealth solutions non-optional. Exploring innovative solutions that emphasize Indigenous health care delivery models that are community directed, culturally safe, and preferably close to their home is crucial. Remote presence technology (RPT) has the potential to achieve these prerequisites for building local capacity for quality pediatric acute care programming.

Staying home for Pediatric Health Care

In 2015, the TRC (2015b) developed Calls to Action, and invited Canadians to improve the conditions for Indigenous peoples by promoting mutual respect through reflection on historical events. Achieving health equity was identified as a key factor in moving towards reconciliation (TRC, 2015b) with mutual respect necessitating direct community and family involvement in health care decision making (Smylie, 2015). Health care equity for Indigenous children may be achieved by facilitating a model of care that works to prioritize Indigenous children receiving health care near their families in or close to their communities.

Telemedicine has been shown to redress disparities in health care access while providing high-quality patient-centered care that is well accepted by both patients and providers (McConnochie, 2006). There is, however, a paucity of literature on its effectiveness and utility in communicating and providing care within Indigenous communities. The nurse practitioner in our study described what she felt was the greatest advantage of virtually moving specialists to local Indigenous communities to deliver acute care. She highlighted that the family and extended family can be present for the interaction, making it family-centered, which is consistent with the priorities of Indigenous culture (Dell, 2015). It is surmised that care close to home with greater family involvement in decision making promotes cultural safety, humility and prevents discrimination within the health provision interaction. Furthermore, leaving home had practical implications for other children in the family and extended family, through loss of employment and the need to find childcare.

The RPT implications for the family network are underpinned by the capacity for some self-determination regarding decision making about children leaving their community for health care. The opportunity to receive health care locally has great meaning and is a high priority for

the family in this case and the majority of others who participated in the CBPR pilot (Holt, 2017). The deep-rooted fear associated with an Indigenous child leaving their home community cannot be understated. This relates to over a century of children being forcibly removed from their homes and communities to attend residential schools, receive treatment for tuberculosis at sanitariums, or to be placed in the child welfare system (TRC, 2015b). Moving care (virtually) to the patient in their home community with the RPT, allows the discussion regarding diagnosis, treatment and possible transfer to be done directly and not over the phone and then translated second hand by local providers to the patients and families. With the RPT, the discussion occurs in the room with the remote presence specialist, the patient, the family and the local health provider. Inherent in the process is the family being involved in real time with the clinical assessment and recommendations for their child. This allows a robust discussion regarding pros and cons of transfer, safe disposition and ongoing follow-up.

The Truth and Reconciliation Commission (2012a) of Canada documented the stories of survivors affected by residential schools. The 94 Calls to Action that bid all Canadians to participate, are explicit about the importance of carrying forward the connection between Indigenous children and their language, culture, and history. Indigenous Elders are the key to maintaining this legacy. Indigenous seniors are commonly the primary caregivers for their grandchildren (Wilson, 2010) and are extremely influential for young generations (Varcoe, Botoroff & Carey, 2010). Multiple limitations can prevent Elders from travel especially long distances to accompany medevac'd children.

The important relationship between Indigenous Elders and children emphasize the reciprocal need for each other's presence especially during vulnerable periods such as health deficiencies. Children and Elders characterize two culturally important cohorts within Indigenous communities (Wilson, Rosenberg, Abonyi & Lovelace, 2010). Therefore, it is compelling that Vanessa was decisive in her recommendation that Elders be the next potential recipients of specialized care through the robot. The connection between those two generations is imperative to ensure that cultural knowledge and language is revived and transmitted (Blackstock, 2011).

Embodiment of the RPT

Despite nearly 600 km physical distance between the patient and the intensive care specialist providers the most significant new finding from this experience-focused study of the

RPT was the sense of sub-specialist presence or ‘being in there’ from all participants. This is consistent with previous literature that has shown that physical distance does not prevent emotional connection or the capacity to communicate effectively during a patient-clinician encounter (McConnochie, 2015). However, an essential determinant of success is that the communication delivers information in an effective manner. Bedside manner has been referred to as the way in which a doctor interacts with patients in order to make them feel comfortable (Silverman, 2012). The common use of this term indicates an inherent importance of this attribute. The question then emerges about how bedside manner occurs through virtual presence, and whether or not physical presence is a requisite for bedside manner. Web-side manner has been presented in telemedicine literature as an analogous term for the remote presence relationship development term that emphasizes the quality of communication (Gonzalez, 2017). Gonzalez (2017) discusses that the quality of communication, and the responsibility a clinician has in integrating an empathetic manner, is no less important in telemedicine than it is for in person communication. The last advantage of virtual presence over telephone advice for remote communities is that all participants (patient, family, Elder) feel integrated within the health care interaction. Interpersonal communication involves more than words. Intonation of voice, body language, facial expression, in interpreting feelings of others and responding to them are all essential for a quality patient-caregiver consult (McConnochie, 2015). This is lost with the telephone. Communication with patients, whether it is in person or through telemedicine, comes with immense responsibility. Our interview data revealed that the study parent, child, local provider and specialist all experienced a sense of human presence during the virtual consultation. The mother described being involved in decision making and the specialist as ‘being in there.’ The child hugged the RPT, the specialist forgot she wasn’t there in person and the local provider felt comfortable to proceed with advanced therapies because she felt it was almost face to face. These findings revealed a connection or relationship with the participants involved and validated successful communication. (McConnochie, 2006).

A critical theme from our study revealed the embodiment of the RPT that occurred. Successful embodiment relates to concepts of cultural safety and humility. How they are integrated ultimately impacts the quality of the RPT care experience. The presence of RPT alone is not sufficient for a quality pediatric health care access solution. Much of this rests on the individual who embodies it. This finding is paramount because simply being a pediatric critical care expert does not mean a positive relationship and quality outcome from the RPT interaction

will occur. This is critical when the provider using the RPT is caring for Indigenous children where cultural humility is only achieved when one reflects on one's own preexisting biases and creates a culturally safe interaction that mitigates systemic racism. Therefore, it is necessary to educate RPT users not only about the technologic aspects but how the essence of successful embodiment can be achieved. The current training process is 45 minutes and focuses on the technology. The process of becoming culturally humble and feeling secure to provide culturally safe care has been a 13-month journey so far and required me reading the TRC documents. This will be a lifelong journey for me no matter by what means I am providing care.

Our study revealed that clinical and therapeutic relationships developed through the RPT. Furthermore, practicing cultural humility is key to the successful development of a quality virtual pediatric acute care experience. This qualitative phenomenological study invited stories of the lived experience receiving and delivering pediatric acute health care through RPT. The interpretation occurred through the lens of concepts related to cultural safety, humility and the Calls to Action of the TRC. The findings can inform the RPT program's viability given proper preparation of those clinicians who embody it. However, the study also revealed risks to its sustainability within our current medical care system that relate back to health care providers and policy makers advancing RPT as a solution. Barriers to the adoption by clinicians are embedded in the perceived additional clinical time required by the RPT, as well for Saskatchewan—the lack of remuneration codes designated for acute virtual presence care. Building capacity in remote communities requires community direction but also relies on the basic infrastructure to support local delivery of care. These are critical challenges to overcome as this innovative and potentially transformative health care access solution moves forward. This thesis studied the perspectives of pediatric acute care delivered through the RPT with a child and her family living on a First Nation, and her local and remote care providers. There are opportunities to explore how this technology supports other population groups in future research. In 2012 all Canadians were invited to respond to the Call to Action from the TRC (TRC, 2012a). Inequitable health care access for Indigenous remote communities continues to perpetuate the gap in health outcomes between Indigenous and Non-Indigenous peoples. As health care providers we must strive to break barriers to allow the integration of health access solutions such as RPT into our current medical model of care.

Strengths and Limitations

Tracey (2010), outlined eight ‘big tent’ criteria for excellent qualitative health research. These included the following: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, meaningful coherence. Our topic is a relevant, timely and interesting, as it presents an inquiry of a medical case that revolves around the issue that remote Indigenous children have poor access to acute health care and an innovative solution using technology may help. Furthermore, it is timely because, as Canadians we have been invited to respond to the Calls to Action of the TRC commission. This study highlights the ongoing barriers that remote Indigenous children have to acute health care access. Creating universal health care access is a priority from the commission’s report (TRC, 2015b). Our study was rich in rigor and coherent in its approach as it bridged with a previous CBPR project and endeavored the challenge of combining traditional Indigenous world views with a western methodology (phenomenology and case report). The combined methodology was used to explore experiences of utilizing a modern technology to solve health access barriers for Indigenous children. The analysis included the construction of whole stories drawn from a medical case description and interview data, as well as the development of codes and themes. Sincerity and credibility were achieved with multiple direct quotes of participant reflections throughout the results section. In addition, transparency regarding my role as both the primary researcher and as the pediatric specialist supports the ongoing sincerity of the study.

In this study I was only able to explore in detail, one case, in one community. However, as a clinician using RPT in additional other communities, the experience has been consistent with this case. It would be interesting to seek a case where the experience may not have been as positive in order to have a better look at what that experience was like.

The topic resonates and is poised to have a significant contribution to decreasing the barriers of distance and time for acute pediatric health care access that perpetuates with our current medical delivery model. It challenges us morally to take responsibility for this egregious health care access gap and begin to explore innovative and culturally safe and respectful health care solutions. The study was approved by the University of Saskatchewan Research Ethics Board and received approval from the FN community. Future research may broaden the examination of experience with RPT in varied patient cohorts and communities.

Conclusion

The powerful forces that are transforming healthcare can generate enormous potential (Guissi, Baum, Plazzoto, Muguerza & Gonzalez, 2017). The utility of RPT as a potential solution to narrow the gap in health care access between Indigenous and non-Indigenous communities is significant. RPT supports a medical delivery system where acutely ill Indigenous pediatric patients can potentially receive care in their home community. Indigenous history and the associated intergenerational trauma oblige us to respond to the TRC Calls to Action and endeavor innovations that align with Reconciliation. Our overarching CBPR qualitative study demonstrated that pediatric acute care delivery in a small northern indigenous community is feasible, prevents frequent transports out of the community and has multiple advantageous implications for the health providers and the family network. Our study's findings support the development of a culturally humble, Indigenous informed RPT pediatric specialist program to promote pediatric health care access equity, with the priority of caring for Indigenous children in their home community when the local diagnostics and treatments can be delivered at home. Expanded roles or the additional time spent virtually connecting is juxtaposed with the inherent benefit that the patient experiences with timely access to specialized care and informed direct communication with the local care providers, family and extended family. The depth of reciprocal learnings through the RPT and the importance of self-determination and cultural humility with Indigenous patients, families and communities cannot be understated. RPT is a nonnegotiable future state of integrated health care delivery that is a transformative strategy to mitigate barriers to health care access for all

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