

Running Head: FIRST NATIONS EXPERIENCES OF RENAL THERAPY

Misipawistik Cree Nation Caregivers' Experiences of a Family Member

Requiring Renal Replacement Therapy in The Pas, Manitoba: A Descriptive Qualitative Study

by

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Abstract

Historical and contemporary factors have impacted First Nations People to the extent that they are at greater risk for diabetes and chronic kidney disease (CKD). Optimal treatment modalities would improve conditions; however, delivery is complex. Explorations on the experience of living with CKD among First Nations are limited. Although discourse about how to care for older First Nations has been taking place for some time in Canada, little research exists on the needs and challenges of caring for family members who live on-reserve with end stage renal disease. This gap is especially notable when First Nations' understandings and conceptualizations of health and wellness are considered. Guided by decolonizing methodologies and two-eyed seeing, this study enlisted a qualitative descriptive approach with snowball and purposive sampling, semi-structured interviews, reflective journals and member checks. Eight First Nation family members volunteered to participate. Participants conveyed a resiliency, subsequent to *Miyopimatisiun* (Cree way of life) across relations with Indigenous and non-Indigenous contexts to fortify care and support of the family member requiring renal replacement therapy (RRT). This study establishes the experiences of Misipawistik Cree Nation caregivers, demonstrates the distinct needs of First Nations individuals, families and communities facing CKD, and supports previous studies on barriers to the wellbeing of Indigenous patients with CKD and caregivers in Northern Manitoba.

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Chapter One: Introduction

Aboriginal is a collective term used to describe descendants of the original peoples of Canada. The Constitution Act of 1982 specified that Aboriginal Peoples in Canada are composed of three groups—Indian, Inuit, and Métis peoples. Because this term was created by representatives of the Government of Canada and places all original peoples into one group, it implies that descendants of original peoples are similar. This name may sometimes be perceived as inappropriate for that reason.

First Nations Peoples is a term that came into common usage in the 1970s to replace *Indian*, a word many found offensive. Despite its widespread use, there is no legal definition for the term *First Nations*. It refers to both Status and non-Status Indians. In addition, some have adopted the term *First Nations* to replace the word *band* or *reserve* when identifying their community. For the purposes of this study, Aboriginal will be used to describe Indian, Inuit, and Métis peoples or when the original source utilized that term. First Nation Peoples refers to people who self-identify as descendants of the original peoples of Canada and may include both Status and Non-status Indians.

In Canada, First Nations have the highest rates of chronic illnesses such as arthritis, diabetes, heart disease, hypertension and cancer in comparison with other groups (Habjan, Prince & Kelley, 2012; Sarker, Lix, Bruce & Young, 2010). In particular, the high rate of diabetes in First Nations has continued since the initial announcement by Young, McIntyre, Dooley and Rodriguez (1985) that the higher rate of diabetes mellitus was found to be statistically significant among First Nations in northwestern Ontario and northeastern Manitoba. The proportion of the Canadian population reporting a diagnosis of diabetes was highest for First Nations Peoples living on-reserve (aged 18 years and older: 15.3%), followed by First Nations individuals living off-reserve (aged 12 years and older: 8.7%) (Public Health Agency of Canada [PHAC], 2011).

Complications associated with diabetes in Aboriginal populations are higher due to an earlier age of onset, a greater severity of the disease, reduced access to health services due to geographical barriers, and an increased number of risk factors for other chronic diseases (PHAC, 2011). Diabetes is the major contributing factor to the rising rates of chronic kidney disease (CKD) and the leading cause of kidney failure among Aboriginal Canadians initiating dialysis (Yeates & Tonelli, 2010).

A condition that has no cure, CKD involves progressive, irreversible destruction of the kidneys that can develop to the last stage of kidney failure known as End Stage Renal Disease (ESRD) requiring renal replacement therapy (RRT) through dialysis or transplantation (Lewis, Heitkemper & Dirksen, 2006). According to the Manitoba Renal Program, in regards to CKD, the amount of damage to the kidneys is categorized by five stages using estimated glomerular filtration rates. As CKD progressively worsens through these five stages, it eventually leads to kidney failure or ESRD. Aboriginal people requiring RRT were significantly younger, were more likely to have diabetes as the cause of ESRD and retained more co-morbidities than non-Aboriginal patients (Yeates & Tonelli, 2010). The incidence of ESRD is twice as common in the Aboriginal population (Habjan et al., 2012).

Aboriginal peoples reside in all areas of Canada; however, remotely located patients present a major challenge for providing renal health care (Bernstein, Zacharias, Blanchard, Yu & Shaw, 2010). The high cost of therapy coupled with the increasing rise in Aboriginal patients warrants extensive and appropriate research. Although discourse about how to care for older Aboriginal people has been taking place for some time in Canada, little research exists on the needs and challenges of caring for family members who live on-reserve with ESRD (Habjan et al., 2012). “This gap is especially notable when we consider the Aboriginal understanding of health and wellness” (Habjan et al., 2012, p. 210).

Significance of the Problem

“Informal caregivers are mostly unpaid family, friends, and neighbours of a care recipient who requires help with activities of daily living” (Horrell, Stephens, & Breheny, 2015, p. 339). Providing care to a family member has known negative consequences for informal caregivers’ health and well-being (Monin & Schultz, 2010). Caregiver burden describes the weight or load carried by caregivers as a result of adopting the caregiver role (Mochari-Greenberger & Mosca, 2012). Informal caregiving for patients with chronic illnesses has been associated with increased caregiver burden (Mochari-Greenberger & Mosca, 2012). The majority of caregiver research has focused on the physical demands of providing care, hypervigilance, and dealing with complex bureaucracies to access support services resulting in increased stress and diminished health of caregivers (Monin & Schulz, 2010). Less attention has been paid to caregivers’ emotional experiences (Monin & Schulz, 2010). Furthermore, even less attention has been paid to caregiving within the context of Aboriginal peoples’ health and well-being (Habjan et al., 2012).

Only one study was located that examined caregiving for Elders in First Nations communities in northwestern Ontario (Habjan et al., 2012). Despite a strong preference for helping Aboriginal people age in their homes and home communities, significant barriers and challenges were identified at the family, community, health system, and social policy level (Habjan et al., 2012). Barriers included a lack of family caregivers, shortage of health care providers and programs, changing community values, and limited access to provincial health services. Another barrier was limited access to culturally relevant and safe care (Habjan et al., 2012). Culturally appropriate interventions are vital to improved health outcomes for this population. Health care providers have been challenged not only to improve the quality of care for Aboriginal people but also to advocate for best practices in developing resilient Aboriginal communities (Barton, 2008).

A study exploring the experiences of Misipawistik Cree Nation caregivers of a family member requiring RRT in The Pas, Manitoba was needed. Understanding Misipawistik Cree Nation caregivers' experiences will facilitate improved services and outcomes for the individual with ESRD, their family, and the community (Canadian Institute for Health Information [CIHI], 2013).

Purpose of the Study

The purpose of this study was to explore the experience of Misipawistik Cree Nation caregivers of a family member requiring RRT in The Pas, Manitoba.

Research Questions

The research question was, "What are Misipawistik Cree Nation caregivers' experiences of a family member requiring RRT in The Pas, Manitoba?"

Standpoint and Assumptions

Integral to qualitative inquiry, the researcher must acknowledge standpoint and any biases and assumptions they may hold (Creswell, 2007; LoBiondo-Wood & Haber, 2013). This is essential for recognizing the inherent preconceived beliefs held by the researcher, which could influence data collection and analysis. Bringing forth and recognizing these notions can help the researcher to minimize possible biases within the study. To mitigate this possibility, I will elaborate on my standpoint and previous experiences acquired in informally and formally caring for people requiring dialysis.

I am a First Nation woman from Misipawistik Cree Nation. "Misipawistik" in the local language means "rushing rapids," which was once a historical landmark before the hydroelectric dam was constructed in the late 1950s. The community is located 400 kilometres north of Winnipeg. It is situated at the mouth of the Saskatchewan River as it runs into Lake Winnipeg. Further information about the research site is provided in Chapter Three.

Prior to my experience as a dialysis nurse, I cared for family members that required hemodialysis. My family has experienced struggles commonly faced by families living with the effects of CKD. I lost significant family members to ESRD and can relate personal experiences of hardship and suffering from the trials of RRT. I see myself as an activist committed to changing the course of CKD in my people. The commitment was the principal reason for the conception and design of this study.

As a dialysis nurse, I obtained experience caring for patients in urban and remote renal health centres. My renal health nursing education was provided in Winnipeg. Upon certification, I provided nursing care in Garden Hill First Nation. Nephrologists' care was delivered through telehealth services or patients were transported to urban units. The staff of this remote renal health unit provided most of the physical and emotional care to these patients and their families. This remote setting allowed me to gain experience in the logistics of providing health care services to First Nations Peoples with chronic illnesses and their families. The duty of providing care to these people necessitated the ability to service equipment, sustain inventory and initiate dialysis on a daily basis. Upholding optimal standards of care and accreditation for the health unit was a constant concern. Providing RRT in a remote setting, accessible only by air or winter road, was challenging.

In this remote setting, I observed that patients and their families spent many hours with sufficient efforts to access or arrange health care services off-reserve. First Nation individuals and their family members were trying to communicate with systems and people that did not seem to understand their situation and often, they then turned to the remote health unit staff for assistance in these matters. Issues would occur when patients were sent to urban centres for referrals or checkups. They often returned with complaints regarding medical transportation and services that stressed them more than the actual medical appointments. These patients and their

families expressed that they felt like they were an item of cargo rather than a person and the patients and their family members appeared to suffer from these off-reserve episodes.

Collaboration with health care providers was a required skill for these patients and their families. They organized their lives around a dialysis schedule. It is a lifestyle that is demanding and has limited flexibility.

Given my standpoint and experience, I acknowledged that I needed to provide a safe space for participants to discuss their experiences without my influence or bias. This process was achieved through awareness of these assumptions and engaging participants with an open mind. The following assumptions were identified based on prior professional and personal experience before the initiation of this study:

1. Caregivers are experts in caring for a family member with ESRD who requires RRT.
2. Caregivers are aware of the prognosis and illness trajectory of their relative's ESRD.
3. Hemodialysis is a challenge for First Nations patients and their families who reside in remote communities without local renal health units.

Definition of Major Constructs

The following major constructs are defined as:

Chronic Kidney Disease (CKD): the presence of kidney damage, or a decreased level of kidney function, for a period of three months or more (Kidney Foundation of Canada, 2013).

Colonialism: the practice by which colonizer's directly control the colonized and impose their expectations of knowledge, experience, culture and language (Denzin, Lincoln & Smith, 2008).

Cultural competence: refers to attributes or characteristics of service providers that equip them to effectively provide otherwise desirable or warranted health care interventions to an array of culturally diverse patients or clients (Wendt & Gone, 2012).

Cultural safety: nursing or midwifery action to protect patients and communities from danger or to reduce the risks of hazards to health and wellbeing while respecting their cultural background (Racine, 2014).

Dialysis: the passage of a solute through a membrane (Venes & Thomas, 2001).

End Stage Renal Disease (ESRD): a continuum of CKD, is defined as irreversible kidney failure treated with dialysis or transplantation (Ganesh & Lee, 2011).

Family: to Aboriginal peoples, family signifies the biological unit of parents and children living together in a household, but it also has a much broader meaning. Family also encompasses an extended network of grandparents, aunts, uncles and cousins (University of Saskatchewan, 2003).

First Nations: refers to the indigenous peoples located in the region of North America that is now Canada who are not Inuit or Métis (Ashcroft, Griffiths & Tiffin, 2013).

Hemodialysis: a procedure in which impurities or wastes are removed from the blood, used in treating patients with ESRD and various toxic conditions (Credo, 2013).

Home hemodialysis: patients and family are trained to perform hemodialysis in the home and care for the vascular access site (Thomas, 2014).

Informal caregivers: mostly unpaid family of a care recipient who requires assistance with activities of daily living. The largest caregiving group is adult children (mostly daughters) or elderly wives. Informal caregivers provide as much as 80% of community care (Horrell et al., 2014). For the purposes of this study, I will use the term “caregivers” because “informal” lacks value and I perceive that family caregivers are respected and valued.

Liminality: is related as the experience of in-between and uncertainty found in persons dealing with illness that is often difficult to talk about or articulate (Molzahn, Bruce & Shields, 2008).

Métis: the unique indigenous peoples descended from the marriages of First Nations and settlers during the conception of Canada, who have been recognized as a distinct people and culture (Ashcroft, Griffiths & Tiffin, 2013).

Peritoneal Dialysis (PD): is a simple technique for renal therapy, predominantly performed by the patients themselves, where the dialysis solution is instilled into the peritoneal cavity, through the use of a catheter, and excess toxins, solutes and fluid are removed via automated or manual exchange therapies (Thomas, 2014).

Renal replacement therapy: the various treatment modalities for renal disease such as hemodialysis, peritoneal dialysis and kidney transplantation (Thomas, 2014).

Renal transplantation: transplantation of the kidney that is considered the treatment of choice for patients requiring renal replacement therapy (Thomas, 2014).

Systemic racism: the imposition and perpetuation of inequities from governance discerned by the unjust distribution of power that is built into law, policy and economic practice (Matthews, 2017).

Chapter Summary

Chapter one provided an introduction to CKD and ESRD among First Nations Peoples in Canada. Diabetes, the principal contributing factor, remains highly prevalent in this population and ultimately progresses to ESRD, which requires RRT in the form of dialysis or transplantation. An incurable condition, the management and experience of ESRD for First Nations patients and families are underrepresented in the literature and needs to be explored. The justification for this qualitative study exploring the experiences of Misipawistik Cree Nation caregivers of a family member requiring RRT in The Pas, Manitoba was introduced.

Chapter Two: A Review of the Literature

This literature review examines the relevant history and pertinent research on CKD, a progressive degenerative disorder that affects the nephrons of the kidney, and the consequences of CKD among First Nations Peoples. To situate this study within the literature, the following topics are explored: (a) health disparities and diabetes within Aboriginal Peoples in Canada; (b) CKD in the Aboriginal population, including treatment options; and (c) the experiences of Non-Aboriginal Canadians and First Nations patients receiving RRT, including their relocation for care. This review of the literature identified limited evidence about the experiences of First Nation caregivers of a family member requiring RRT in remote geographical settings.

Health Disparities among Aboriginal Peoples in Canada

Disparities in health or health disparities are a major public health and social justice concern as less affluent members of the population suffer from a disproportionate amount of mortality and morbidity than those who are better off (Frohlich, Ross & Richmond, 2006). In Canada, the health disparities that exist among First Nations People are attributed to the proximal (i.e.: health behaviours, physical and social environment), intermediate (i.e.: community infrastructure, resources, systems and capacities), and distal (i.e.: historic, political, social and economic contexts) determinants of health (Adelson, 2005; Reading & Wien, 2009). Reading and Wien (2009) noted, “individuals, communities and nations that experience inequalities in the social determinants of health not only carry an additional burden of health problems, but they are often restricted from access to resources that might ameliorate problems” (p. 2). From First Nations Peoples’ perspectives, health and well-being is achievable with disorders like CKD (Douglas, 2013); henceforth, the term well-being will be used in this thesis to describe the view of health and well-being held by Aboriginal people.

Within the environment, engagement with various cultural, social, and economic conditions, recognized as social determinants of health, will serve to affect the well-being of individuals and communities (Richmond & Big-Canoe, 2011). Amidst First Nations communities, the cumulative effects of the various social determinants of health are associated with the diminished quality of physical, mental, and emotional well-being (Reading & Wien, 2009). Examples of factors in the social determinants of Aboriginal peoples' health include historical oppression, systemic racism, gender, education, housing, employment and working conditions, and health services (Douglas, 2013; Mikkonen & Raphael, 2010; Reading & Wein, 2009). The remainder of this section will outline the ways in which historical repression and racism, education, gender, and housing and working conditions have impacted the well-being of First Nations/Aboriginal Peoples to the extent that they are at greater risk for diabetes and CKD.

Impacts of Historical Oppression and Systemic Racism

For Aboriginal people, the dispensation of a repressive colonial system has moulded conditions of physical, psychological, economic and political disadvantage which has devastated the well-being of generations of First Nations people (Reading & Wein, 2009). The enactment of colonialism projects that the perspective of the colonizers on the history and significance of the colony will effectively deny other views of these circumstances and what they mean to the people that are colonized (Smith, 2012). Consequently, many Canadians appear disconnected to the conditions in First Nations communities (Spence & White, 2011).

Keilland and Simeone (2014) reported that half of on-reserve people had moderate to high levels of psychological stress and a rate of suicide that is twice as many as the general public (24 versus 12 deaths per 100,000 individuals). Likewise, the Aboriginal population accounts for 8% of people living with HIV and 12.5% of new infections in 2008, experiences rates of tuberculosis at 26.4 times the rate of non-Aboriginal people, and witnesses their women

as 3.5 times more likely to experience violence as other Canadian women (National Collaborating Centre for Aboriginal Health [NCCA], 2013). Gionet and Roshanafshar (2013) identified smoking rates over two times higher for Aboriginal people who are twice as likely to be exposed to second-hand smoke. “Aboriginal adults had higher obesity rates: First Nations people—26%; Inuit—26%; and Métis—22%; compared to 16% for non-Aboriginal adults” (Gionet & Roshanafshar, 2013, p. 3). In Canada, the prevalence of chronic conditions associated with activity limitation among First Nations and Inuit populations were highlighted by these percentage rates: 24% with hypertension, 28% with diabetes, 33% with arthritis, 36% with heart disease, and 38% with cancer (Reading, 2009). Aboriginal peoples suffer more debility in comparison with the Non-Aboriginal population in Canada.

Intersection with gender. Aboriginal men are three times more likely than non-Aboriginal men to experience violence by authorities or individuals (Brownridge, 2010) and 25% of adult men in sentenced confinement are Aboriginal (Dauvergne, 2012). There is no accurate data on homeless Aboriginal people, but a study using predominantly male Aboriginal youth estimates that 15% to 40% of Aboriginal men may be homeless across Canada (Baskin, 2007). Reports that described Aboriginal people with a mental health problem traced occurrences from hospital records and observed that First Nations men are admitted for substance use more often than others (Khan, 2008). These numbers indicate greater suffering for men of First Nations, Inuit or Métis lineage than the rest of the Canadian male population. For Brian Sinclair, an Aboriginal man trying to seek health care, the impact of systemic racism proved fatal (Allan & Smylie, 2015).

The literature infers that Aboriginal men in Canada are experiencing a distressing amount of harm and the outlook for Aboriginal women is much worse. “Indigenous women in Canada carry a disproportionate burden of ill-health and disease...including higher rates of hypertension,

heart disease, diabetes, cervical and gallbladder cancer, HIV/AIDS, substance abuse, mental illness and suicide” (Allan & Smylie, 2015, p. 15). First Nations, Inuit and Métis women experience four times more violence than non-Aboriginal women, and face greater risk for harassment by authorities (Loppie, Reading & de Leeuw, 2014) as well as acts of structural violence in health care (Kurtz, Nyberg, Van Den Tillaart & Mills, 2008) . This may be linked to the fact that Indigenous/Aboriginal women account for one third of women in federal prisons, reflecting a 90 percent increase over the past ten years (Wesley, 2012). Moreover, the severity of violence against Aboriginal women is demonstrated in the mass numbers of missing and murdered Indigenous girls and women in Canada (Allan & Smylie, 2015) with a national inquiry.

To Aboriginal Peoples, systemic racism results in profound negative effects on the physical, emotional, spiritual, and mental health of families and communities, and accentuate the overflow of children in the care of child welfare agencies. Aboriginal children represent 48 percent of children in care with estimates much higher in Manitoba, British Columbia and Saskatchewan (Allan & Smylie, 2015). In Saskatchewan, First Nations and Métis children make up to approximately 80 percent of children in care. The toll on families and communities of Aboriginal People is devastating and presses for a further consideration to enhance the living and working conditions that prevails among these populations.

Intersection with poor living conditions. Life in Aboriginal communities in Canada does not coincide with the same standard of living as the Non-Aboriginal population. First Nations in Manitoba rated conditions such as access to recreational facilities, housing, streets and roads, and household drinking water as poor (Adams, 2011). From 2007 to 2010, the Council of Canadian Academies (2014) marked that 27% of Inuit, 22% of First Nations people living off-reserve, and 15% of Métis described being food insecure, compared to 7% in the general population. Aboriginal families had a rate of food insecurity more than double (27%) that of all

Canadian households (12%). Across Canada, 135 drinking water advisories, which protect the public from contaminated water, were granted to 90 First Nations communities (Health Canada, 2015).

Intersection with problematic access to health care. Inuit, Métis and First Nations adults reported a lower level of health than non-Aboriginal adults even when socioeconomic, health care access and lifestyle risk factors were brought into account (Garner, Carriere, Sanmartin & LHADRT, 2010). In contrast to the rest of Canadians, 35% of First Nations perceived that access to health care services was deficient, and 18% indicated they had not secured essential health care in the past year versus 12% for the Non-Aboriginal population (Cameron, Pilar Carmargo Plazas, Santos Salas, Bourque Bearskin, & Hungler, 2014).

Intersection with limited education. Among Aboriginal population in Canada, Gordon and White (2014) projected that by 2021, more than a quarter million people will not have a high school education, indicating a high unemployment rate of 23.3% without high school; 11.4% with high school, and 9.3% with any secondary education. These social conditions are prompting Canadian renal health professionals to demand urgent consideration of the challenges facing providers and patients including system complexity, remote living location, low socioeconomic status and language and cultural differences (Anderson, Yeates, Cunningham, Devitt, & Cass, 2009).

Richmond and Big-Canoe (2011) urged health researchers and policy-makers to comprehend the way that social determinants of health function in the daily lives of people to influence their health and health behaviours. Fundamentally, research and policy must reflect the contemporary realities of Aboriginal well-being which includes individual and community-based impacts of health disparities (Adelson, 2005). Through incorporating descriptive qualitative research findings into revised policies and procedures, improved models of care may be

implemented and evaluated in partnership with First Nations Peoples to reduce health disparities and add to the enrichment of nursing knowledge and practice development. This is going to be especially necessary to address the epidemic of diabetes in the Aboriginal population that is often correlated with health disparities and the conditions of these communities.

Diabetes in the Aboriginal population

While increasing rates of diabetes mellitus (hereafter referred to as diabetes) have been associated with high human costs within the Canadian population, the human costs within the First Nations population of Canada are significantly higher. Within the past ten years, diabetes has risen from 3.3% to 5.6% among Canadians which translates to more than 2.3 million people living with diabetes (PHAC, 2011). In contrast, the prevalence of diabetes in the Aboriginal population is 17.2% among First Nations living on reserve, 10.3% among First Nations living in urban areas, 7.3% among Métis and 5% among Inuit (PHAC, 2011). Aboriginal communities are growing at double the rate of the general population, and in 2016, the proportion of Aboriginal people in Canada rose from 3.4% to 4.9% (Statistics Canada, 2017). Considering that more than 1.6 million people identified as Aboriginal in 2016 (Statistics Canada, 2017), this translates into conservative estimates of 70,000 to 240,000 people of Indigenous lineage living with diabetes in Canada. Mitigating factors in the social determinants of health evidenced as health disparities (Masuda, Zupancic, Crighton, Muhajarine & Phipps, 2014) are contributing to the increasing rates of chronic disease in the Aboriginal population of Canada as well as the likelihood of acquiring quality health care in relation to that health issue such as diabetes and its complications.

A higher prevalence of diabetes in Aboriginal populations translates to increased risks of developing CKD due to their younger onset of diabetes and poor glycemic and blood pressure control (CIHI, 2014). In 2004–2006, the incidence of diabetes in Aboriginal youth was 23.2

cases per 100 000 youth (Millar & Dean, 2012) with northern Manitoba and northwestern Ontario claiming the highest rates of cases, compared to an overall rate of 1.56/100 000 children across Canada. In First Nations youth aged 4–19 years, Millar and Dean (2012) found the prevalence of diabetes was 1.1% and intensified to 4% among adolescent females, indicating an unprecedented rate of the condition amid a segment of the population that had not experienced such effects before. The challenge for adequate diabetes management is complicated by the small size and remote locations of Aboriginal communities across Canada along with high turnover of non-Aboriginal professional staff (Hayward et al., 2012). These factors combine and contribute to the growing numbers of First Nations people with diabetes-related ESRD and other chronic diabetic complications (Jaing et al., 2014). The magnitude of diabetes related complications is significant with substantial prevalence rates of diabetic nephropathy (>50%) found among First Nations compared to the other populations (Hayward et al., 2012; Naqshbandi, Harris, Esler & Antwi-Nsiah, 2008).

In all populations, the continuous assault on the nephrons of the kidney caused by the symptoms of diabetes, including hypertension, results in scarring and damage to tissue that decreases renal function and contributes to the development of CKD (Thomas, 2014). For Aboriginal Canadians, diabetes is the primary cause of CKD which affects care for ESRD patients, particularly in kidney transplants and access to treatment (CIHI, 2014). The next section of this review will examine the available literature on CKD in the Aboriginal populations.

Chronic Kidney Disease in the Aboriginal Population

Between 2007 and 2009, an estimated 12.5% of adults in Canada were living with CKD, which represents about 2.9 million adults with any CKD and 0.73 million with latter stages of the disease (Arora et al., 2013). Gao et al. (2007) reported a prevalence of severe CKD approximately two-folds greater among First Nations compared with non–First Nations people.

In British Columbia, there are more than 19,000 Aboriginal people with CKD and well over 100 in need of a kidney transplant (*Comox Valley Record*, 2014). Examination into further Canadian regions locates a reassessment of diabetic cases that classifies the risk of kidney disease as 2.66 times higher among First Nations participants than among non-First Nations participants (Jiang, Osgood, Lim, Stang & Dyck, 2014) and a screening of First Nations communities in which 30% of individuals were found to have CKD stage two or greater (Ashton & Duffie, 2011). Although the definitive amount of First Nations individual livings with CKD in Canada is not available, these descriptions indicate a prevalence of the condition among the population that is enlarging in scope.

Table 1.

Terminology for and stages of CKD

Table One. Terminology for and stages of chronic kidney disease (CKD)			
Stage	Description	GFR, ml/min per 1.73 m ²	Action
–	At increased risk	≥ 60 (with chronic kidney disease risk factors)	Screening; CKD risk reduction
1	Kidney damage with normal or increased GFR	≥ 90	Diagnosis and treatment; treatment of comorbid conditions; slowing progression; CVD risk reduction
2	Kidney damage with mild decreased GFR	60-89	Estimating progression
3	Moderately decreased GFR	30-59	Evaluating and treating complications
4	Severely decreased GFR	15-29	Preparation for kidney replacement therapy
5	Kidney Failure	< 15 (or dialysis)	Kidney replacement (if uremia present)
Adapted from Levey et al. (2003). National Kidney Foundation practice guidelines for chronic kidney disease: Evaluation, classification, and stratification. <i>Annals of Internal Medicine</i> , 139(2), 137-147			

Note: Reprinted from *Demystifying chronic kidney disease for others*. By E.F. Ravenscroft, 2006, *Canadian Association of Nephrology Nurses and Technologists Journal*, 16, p. 46. Copyright 2006 by the Canadian Association of Nephrology Nurses and Technologists.

Persons with significantly impaired kidney function are at increased risk for ESRD, classified as the final stage of CKD and necessitating substantial therapeutic intervention. In Canada, 41,252 people are receiving treatment for ESRD with the highest prevalence rates in Newfoundland and Manitoba (CIHI, 2014). As a geographically expansive country, Canada has extraordinary challenges in health care delivery and disease surveillance (Komenda et al., 2015), contending to coverage issues in Manitoba. Manitoba has the second highest prevalence rate of ESRD patients in Canada with 1,559.6 rate per million population (RPMP), just under Newfoundland with 1,576.1 RPMP (CIHI, 2014). Komenda et al. (2015) noted a disproportionate increase in the incidence and prevalence of ESRD, described as an escalation of 12-fold in the population in northern Manitoba. Residents in remote northern communities experience limited access to health care resources, which is significant because other social determinants of health compound the limited access to health care such as race, poverty, inadequate housing, and limited food security (Bruner & Chad, 2014; Komenda et al., 2015).

The need to promote and manage renal health among First Nations rose from the initial detection of high rates of diabetes in the Aboriginal population in Ontario and Manitoba (Young, McIntyre, Dooley & Rodriguez, 1985). In November of 2014, over 4500 renal health consults occurred in Manitoba and approximately 1500 Manitobans received treatment for ESRD (MRP, 2014).

First Nations communities are at increased risk of having new or existing ESRD patients who will likely travel greater distances to receive ESRD treatment and are less likely to receive transplants (CIHI, 2013). According to the CIHI (2013), Aboriginal peoples were more than three times as likely to be ESRD incident cases as non-Aboriginals (age-standardized rate of 42

versus 13 per 100,000 in 2011), and were almost three times as likely to be ESRD prevalent cases as non-Aboriginals (age-standardized rate of 267 versus 99 per 100,000 in 2011).

Treatment Options for Chronic Kidney Disease

In the following section, I describe the four treatment options for CKD. A review of these treatment options is necessary to address what is known and what is not known about First Nations' experiences.

In 2012, the collective of Canadians living with ESRD consists of 17,438 (42%) transplant and 23,814 (58%) dialysis patients, including 5,431 new patients who began RRT (CIHI, 2014). The types of RRT offered to new patients are peritoneal dialysis, hemodialysis (home or unit), and transplant (CIHI, 2014) with variations in and between the techniques encompassing factors such as frequency and access (Thomas, 2014).

Approximately 79% of newly diagnosed patients with ESRD initiated RRT through hemodialysis (CIHI, 2014). Dialysis care costs were estimated as \$55,466/year/person in Canadian dollars (Komenda, Gavaghan, Garfield, Poret, & Sood, 2011). These costs do not encompass treatment requirements prior to an initiation of RRT nor other costs that may accompany the course of treatment. Currently, the cost ranges from \$38,658 per person annually for peritoneal dialysis to \$64,214 per person annually for in-centre facility hemodialysis and upwards of \$250,000 per person annually for in-centre facility hemodialysis in remote communities (P. Komenda, personal communication, June 1, 2018).

In Canada, the dilemma lies in providing access to efficient therapy to a diverse population in various and challenging environments. The expense and distance of treatment is greater for First Nations with ESRD since "standard hemodialysis involves treatment three times per week in a hospital or community dialysis unit, with sessions lasting up to four hours" (CIHI, 2013). The majority of new patients in Manitoba begin RRT on hemodialysis (MRP, 2014). In

2018 in Manitoba, the total number of individuals with ESKD was 1272 (P. Komenda, personal communication, June 1, 2018).

Efficient modalities with features more suitable to some patients include peritoneal dialysis (PD), home hemodialysis (HHD) and transplantation. PD and HHD allow therapy at home while a kidney transplant offers a known higher quality of life (Thomas, 2014). Any of these treatment options would improve conditions for patients living with CKD, except each is complex to deliver to First Nations People and communities (Hildebrand et al., 2010; Zacharias et al., 2011; CIHI, 2013).

Peritoneal dialysis. In terms of modalities, PD is usually the first choice of treatment for ESRD in First Nations (Hildebrand et al., 2010); however, this option is rarely chosen (Iliescu, Yeates, McComb & Morton, 2006). In 2012, 16.5% of new patients with ESRD in Canada started initial treatment with PDs (CIHI, 2013). Fine, Cox and Bouw (1993) and Sood et al. (2010) demonstrated that First Nations status is associated with an increase in susceptibilities toward mortality and complications of peritonitis. The increased risk is troubling because it accords a worse prognosis, including recurrence, catheter loss, hospitalization, and technique failure to First Nations who are frequently female, obese, younger, and living farther from their primary health care centre than a non-First Nations counterpart (Hildebrand et al., 2010).

Technique failure is more common in young Aboriginal Canadians (≤ 50 yrs) on PD and could relate to compliance, monitoring and the social determinants of health (Sood et al., 2012). Since the data is statistical and broad by nature, the contextual bases of these results are not clear. However, the contention for PD rests in its lower cost of approximately \$26,000/year per patient (Komenda, 2014) and the simplicity of the system which urges for a careful assessment of ways in which outcomes might be improved among First Nations communities (Prakash, 2011).

Home hemodialysis. Home hemodialysis is a cost effective option at approximately \$40,000/year per patient (Komenda, 2014) and 14% of Manitoba patients choose PD (CIHI, 2014). Guidance of the Manitoba Renal Program in the form of human and physical resources has increased the use of HHDs by 28% since its implementation, which resulted in 71 additional patients using HHD (CIHI, 2014). The therapy alleviates the demand on health care space and workers (CIHI, 2014). Zacharias et al. (2011) advised that despite its challenges, including housing, water supply, medical support and delivery of supplies, safe HHD is possible in remote communities of northern Manitoba. During the period of their study, five patients who opted for HHD lived in First Nations communities, with three residing in remote fly-in communities (Zacharias et al., 2011). HHD costs are substantially lower than in-center hemodialysis plus the benefits related to quality of life have been reported (Komenda et al., 2011). The limited uptake of this preferential RRT is a dilemma that compels serious rectification.

Targeted screening programs in First Nations communities have commenced with an emphasis on prevention and early detection to enhance support for high risk populations and individuals in making informed, healthy decisions on the methods that will impact disease progression (Komenda, 2014; Manitoba Health, 2015). More specifically, the challenges that are facing the viability of HHD in First Nations communities can emerge utilizing methods and approaches that support patients and families living with ESRD.

In-center hemodialysis. The majority of patients in Canada being treated for ESRD are opting for hemodialysis in urban or local health centres. A review of national data verifies that hemodialysis provided in center or an institutional setting (45%) is the most common form of RRT (CIHI, 2014) and necessitates costs to health care of approximately \$83,000/patient/year (KFC, 2013). Dialysis is a more common treatment therapy than transplantation, and the bulk of both Aboriginal and non-Aboriginal patients receiving dialysis are on hemodialysis (CIHI, 2013;

Hemmelgarn, 2006). These conditions may contribute in part to lower dialysis survival rates for Aboriginal patients because figures show that one-third of Aboriginal patients live in remote areas and one in five needs to travel over 250 km to receive treatment for ESRD (CIHI, 2013).

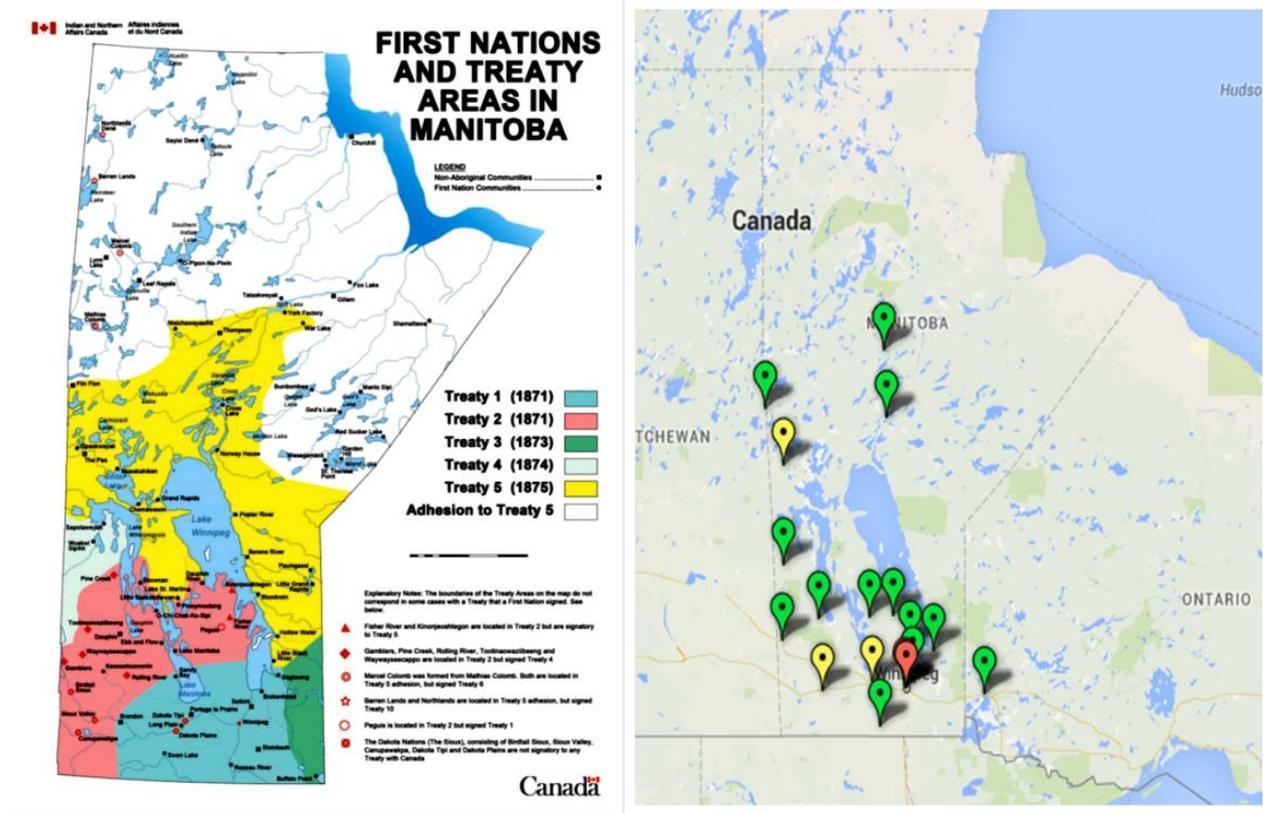


Figure 1. Map of First Nations and treaty areas alongside another of dialysis centres in Manitoba, 2014. Data of First Nations and Treaty Areas in Manitoba from Indigenous and Northern Affairs Canada (2017) and Dialysis Centres in Manitoba from the Winnipeg Free Press (2014).

Despite a reported peak in incidence and prevalence of ESRD in sectors of Canada, the scale of patients with ESRD in Manitoba continues to increase, climbing to the highest incidence and prevalence of ESRD and the highest use of dialysis in Canada (Komenda et al., 2015).

Dialysis patients in remote and rural regions of northern Manitoba are more likely to be of Aboriginal descent and to have socioeconomic conditions associated with poor health outcomes,

such as diabetes, stress, poverty, oppression, unemployment, and lower levels of formal education compared to other Manitobans (Komenda et al., 2015).

Renal transplantation. The remaining option, a kidney transplant, requires major surgical intervention and commands a daily intake of several medications. However, the patient can enjoy a higher quality of life with a reduction in visits to health care (Thomas, 2014). Forty-two percent of Canadians being treated for ESRD are living with a functioning kidney transplant (CIHI, 2013). Comparatively, a survey of Aboriginal and non-Aboriginal patients show that Aboriginal ESRD patients were less likely to receive kidney transplants (27% versus 42%, respectively) controlling for age, sex and diabetes (CIHI, 2013). As well, it is acknowledged that potential living donors to Aboriginals are likely to be excluded for non-medical reasons, chiefly due to loss of contact (96%), which accentuates the need to determine why these persons are lost to follow up and do not finalize the recruitment process (Dunsmore, Karpinski, Young & Storsley, 2011).

Reduced transplant rates are linked to lower socioeconomic status, language and cultural factors including mistrust, discrimination, and traditional healing methods (Bennett, Manderson, Kelly & Hardie, 1995; Promislow et al., 2013; Stephens, 2007). Practices providing an insight of the conditions that contribute to these discrepancies and interventions specifically targeting First Nation communities are required (Dunsmore et al., 2011; Promislow et al., 2013). It is essential to grasp the root causes behind the low rates of kidney transplantation and uncover the factors that hinder the experiences of First Nations individuals, families and communities (Hemmelgarn, 2006).

Experiences of Canadian and First Nations Patients Receiving Renal Replacement Therapy

A survey of Canadian adults with ESRD identified themes such as gaining knowledge, maintaining quality of life, sustaining psychosocial wellbeing, and ensuring appropriate care as

central to patients who have CKD (Barnieh et al., 2014). Patients sought knowledge and were concerned about their freedom to travel, overall wellbeing, and care delivery (Barnieh et al., 2014). Patients' and their caregiver's psychosocial and financial support were escalating necessities nearing the start of dialysis as the treatment option. These themes bear considerable similarities to earlier studies on the experiences of individuals with CKD (Anderson, Cunningham, Devitt, Preece, & Cass, 2012; Anderson et al., 2009; Bennett et al., 1995; Kolewaski, Paterson, Yeates, & King-Van Vlack, 2010; Molzahn et al., 2008; Salvalaggio, Kelly, & Minore, 2003; Wilson, Krefting, Sutcliffe, & Van Bussel, 1994).

Liminality. Descriptions of patients' experiences of CKD by Ravenscroft (2005) and Harwood, Locking-Cusolito, Spittal, Wilson, and White (2005) reveal degrees of patients' stress, antipathy, learning, and adjustment to the condition prior to dialysis as patients yearn for more interaction with health care professionals. A secondary analysis of narrative data by Molzahn, Bruce, and Sheilds (2008) described patients' experiences of liminal spaces or areas of uncertainty. Liminality is related as the experience of in-between and uncertainty where CKD patients are neither completely certain or completely uncertain. Hence, they are in-between or experiencing ambiguous spaces including living/not living, independence/dependence, restrictions/freedom, normal/not normal, worse off/better off, and alone/connected (Molzahn et al., 2008). This liminal experience or feeling of uncertainty is a common thread within the depiction of experiences of CKD (Costantini et al., 2008; Harwood, Locking-Cusolito, Spittal, Wilson, & White, 2005; Molzahn et al., 2008; Pelletier-Hibbert & Sohi, 2001; Polaschek, 2003; Sondrup, Copland, Black, & Trask, 2011).

Studies attending to the spiritual and emotive aspects of patients with CKD demonstrate the psychosocial supportive care needs of these individuals, generally characterized as hope and inspiration (Davison & Jhangri, 2010; Schick Makaroff, Sheilds, & Molzahn, 2013). The

experience of living with CKD for adults in Canada is a life of determination, "... to find a balance between illness and normalcy in their lives" (Ravenscroft, 2005, p. 506). Liminality can be minimized through effective communication and relationships with health care providers that are tailored to Indigenous populations.

Interpersonal Relations. An important part of maintaining well-being appears to lie in the communication between health care professionals and patients with CKD as well as the involvement of family and/or friends (Harwood et al., 2005; Ravenscroft, 2005; Schick Makaroff et al., 2013). A review of studies on the caregivers' experience when caring for individuals with ESRD by Quinan (2005) revealed reports of feeling stressed and overwhelmed with the experience which constitutes a serious exertion on this caregiver group. This finding coincided with the appraisal by Murray et al. (2008) that found interpersonal relationships as one of four factors that influence decision-making in CKD. Patients with CKD typically have a need for individually adapted information as opposed to the typical, generically applied material supplied in a brochure or handbook.

Different Explanatory Frameworks

Perceptions of CKD. As recognition of the current reality of patients facing multiple decisions throughout the trajectory of CKD, health care professionals must consider social, emotional and practical matters as well as biomedical concerns (Murray et al., 2008). Hutchinson (2005) noted, "although the nephrology team is well-equipped to deal with the medical and technical aspects of care, it is less well-equipped to help patients with the impact of the difficult human transitions that come with dialysis and transplant treatment" (p. 270). Probing into nurses' psychosocial interventions with patients and their families living with CKD, Thirsk, Moore and Keyko (2014) noted that nurses' insight into patient behaviour shaped the interventions they offered to patients and their families. Being reflective of one's perceptions

may help nurses assist patients in determining how to adapt to the new life state that they find themselves in (Braun Curtin, Mapes, Schatell, & Burrows-Hudson, 2005).

Informants of a study eliciting facilitators and barriers to home dialysis selection distinguished numerous factors that favoured or opposed this decision for adults with ESRD in Canada (Osterlund, Mendelsohn, Clase, Guyatt, & Nesrallah, 2014). The large number of factors underscores the struggle and the extent of resources required by health care professionals. Despite mounting enthusiasm and availability of resources, Canada has lapsed in the use of home based therapies for patients with ESRD, over the last decade, dropping far beneath in-centre hemodialysis (Osterlund et al., 2014). This lapse is occurring even though research shows that satellite hemodialysis improved access to services for patients with ESRD and enhanced their quality of life (Organ & MacDonald, 2014). In health systems and in society, care or caregiving does not carry the influence it ought to command and, lacking an intellectual agenda, is not given prominence in research or teaching (Kleinman, 2015). There are vast opportunities for health care professionals to assist patients and their families to prepare, adapt and understand the impacts that CKD brings to their lives (Barnieh et al., 2014; Pelletier-Hibbert & Sohi, 2001). Health systems need to fortify the reciprocal bond and trust which are found in authentic caregiving relationships and facilitate these acts in public policy and social programmes (Kleinman, 2015).

First Nations' Experiences of CKD

Studies that explored the experience of living with CKD among First Nations are limited. The few located studies indicated that relocation for patients with ESRD cannot be the solution yet it remains a consistent outcome. Relocation from their home communities to access RRT disrupted social support patterns and created psychosocial stress for First Nations patients with advanced kidney disease. First Nations patients described homesickness, family separation, and

increased financial expense in relocating for dialysis (Wilson et al., 1994). A further exploration of the experience of First Nations dialysis patients reported: increased pain and difficulty in activities of daily living; loss of defined role, independence, and enjoyment in eating; limitations of physical mobility and recreational pursuits; separation from family and community as well as shared traditional recreational activities; economic loss, and psychological challenges (Salvalaggio et al., 2003).

One study in Eastern Canada related the experience of Cree from the Mushkegowuck Territory who relocated to Kingston for hemodialysis (Kolewaski et al., 2010). Dialysis therapy was directly associated with perceptions of well-being, family life, daily activities and social roles. The participants' drawing of a transplanted tree depicted their illness experience while living in Kingston (Kolewaski et al., 2010, p. 133). Divergent health beliefs or concepts influenced the capacity to relate between providers and patients (Kolewaski et al., 2010). Considered to be a fitting analogy for their circumstances, the patients equated their life to the transplantation of a tree that struggles to grow in foreign soil. The analogy has become even more appropriate as access to treatment and transplantation are the prime topics in research on ESRD and First Nations in Canada, as reflected through current evidence and major themes in the literature.

Similar results were noted in Indigenous Australian patients' experience of hemodialysis. The extent and implications of social hardships increase the challenge of coping with an already demanding treatment, and are further impaired through communication difficulties that can often take patients to the breaking point (Anderson et al., 2012). The majority of patients reported attempts to maintain wellbeing, "however, there was also a sense that patients, isolated from family and support networks, became worn down and lost motivation over time" (Anderson et al., 2012, p. 6). The evidence justifies further exploration into the experience of dialysis from the

perspective of patients and family who remain in the community. For Indigenous patients with ESRD, a loss of motivation punctuates the mounting despondency of being separated from their people and environment.

The capacity of health care providers to understand the experience of First Nations people with ESRD and their caregivers are areas of increasing concern. In the analogy by Kolewaski, Paterson, Yeates and King-Van Vlack (2010), a tree that grows in foreign soil needs special attention and considerable care to flourish. Engagement in strategies that facilitate more effective interpersonal communication in the therapeutic setting for First Nations patients and families is critical to addressing CKD in the population (Farragher, Elliott, Silver, Lichner & Tsampalieros, 2015; Traino, 2014).

Impact on family and community. The model of health or wellness in the First Nations context involves physical, emotional, mental and spiritual aspects of an individual that is undeniably bound to family and community (Adelson, 2005; Martin & Yurkovich, 2014). Suri et al. (2011) noted that unpaid caregivers of patients with ESRD have substantial responsibilities associated with increased depression and reduction in quality of life. This finding was contrary to health care professionals' perceptions of family caregivers (Guberman, Lavoie, Pepin, Lauzon, & Montejó, 2006), and illustrates the resistance of health care providers to examine the holistic requirements of First Nations individuals, families and communities responding to the spread of kidney disease.

For family members who provide care in Canada, Spinks and Battams (2014) noted 44% of caregivers were aged between 45 – 64 years with 60% of caregivers were managing this responsibility along with an occupation. Family caregivers undergo emotional aspects related to caregiving responsibilities and readily put their life on hold to assist family members (Horrell, Stephens, & Breheny, 2015), which diminishes healthy behaviours (Mochari-Greenberger &

Mosca, 2012). Family caregivers in First Nations communities eventually become exhausted by the responsibilities of care and cannot access support through the current health care system (Habjan et al., 2012). There is a substantial effect to the community when family members exhibit unhealthy behaviours which increase the risks of acquiring a chronic physical or mental illness and diminishes the ability to help others (Mochari-Greenberger & Mosca, 2012). Nevertheless, a review by Monin and Schulz (2010) on caregiver reactions to the suffering of family indicated that reduced distress in the care recipient improved caregiver wellbeing. Family caregivers are important persons in the prevention and management of chronic illness impacting First Nations patients and families in Canada, and should be established as primary agents in the containment of disease (Habjan et al., 2012).

The consequence of health care policies which fall short of engaging First Nations families and communities in primary prevention strategies is clearly evident. Gaps in treatment for First Nations, observed in the management of diabetes prevention, are contributing to the increased rates of nephropathy and kidney failure in these communities (Hayward et al., 2012; Naqshbandi et al., 2008). Optimal treatments for ESRD such as home hemodialysis, which can be provided in the home with the support of family and community, are not readily extended to First Nation patients that reside in northern areas of Manitoba (Zacharias et al., 2011)

Nurses urgently require expertise in the processes of public policy planning, implementation and evaluation to aim for universality in health care and enhance the development of nursing knowledge and practice (McGibbon, Mulaudzi, Didham, Barton & Sochan, 2014). First Nations families and communities that have been impacted by ESRD are seeing limited or a negligible amount of support from the Canadian health care system (Habjan et al., 2012), and may be placing their own health at risk while still providing care that is considered essential to the whole enterprise (Kleinman, 2015). It is a prospect which is

compounded by the complexity of systemic frameworks that service the wellbeing of Aboriginal people in Canada.

A complex health care system for First Nations. The nature of the Canadian health-care system for Aboriginal people is complex with policies, programs and jurisdictional issues which add to the confusion (Allan & Smylie, 2015; Lavoie & Gervais, 2011; O’Neil, 1995). In the provision of health care for First Nations, relocation assistance lasts for three consecutive months and consists of accommodation, transportation, and three meals a day during the initiation of therapy for hemodialysis (Kolewaski et al., 2010; Health Canada, 2012). As well, the lack of seamlessness across administrations of health (federal, provincial, local) increases harm to the individual because patients can miss social and cultural events, such as funerals, memorials, graduations, or other significant community events, such as gatherings, ceremonies and hunts (Kolewaski et al., 2010). Disruptions to family process, patterns and function that arise from the treatment of ESRD can be attributed to the nature of administrative health policies in Canada and as such, policies should be amended to reduce the disturbance to First Nations living with CKD.

Alternatives are necessary because, “there continues to be a delay, certainly in Manitoba, in early detection and implementation of effective treatment strategies” (Komenda, 2011), such as targeted screening measures and appropriate health information tools. This points to the need to learn about the experiences of ESRD patients and their families. In particular, it is important to learn how personal, family and community factors may relate to improved outcomes, since ESRD among Aboriginal peoples is not only a physical health issue but also one of mental, emotional and spiritual well-being (CIHI, 2013). A better understanding of the cultural factors and domains of well-being for Aboriginal peoples will help inform appropriate models of care,

which could ultimately improve outcomes in First Nations well-being (Wilson & Rosenberg, 2002).

“Understanding the role of ‘place’ as a barrier to accessing care, and the lived experiences of Aboriginal patients, emerged as key research priorities” (Anderson et al., 2009, p. 390). Learning about the experiences of family and community could provide a holistic and accurate portrayal of the challenges and supports encountered by First Nations in Canada who must deal with declining kidney function. Only by breaking down these gaps in knowledge to raise awareness and establishing a sound plan for kidney health care that is appropriate to the patient and the population will stem the tide of CKD in Canada (Ryz et al., 2015). Therefore, a study about the caregivers’ experience of caring a family member requiring RRT in a remote community is warranted.

Chapter Summary

This chapter examined the history and pertinent research on CKD and the consequences of the chronic condition to First Nations populations. An introduction to these topics was followed by an investigation of health disparities and diabetes in the Aboriginal population of Canada. An exploration of CKD in the Aboriginal population was considered as well as the various treatment options that are available. Also examined were the experiences of First Nations patients that are receiving RRT which can ensue into the need for relocation. The significance of limited evidence on First Nation caregivers’ experience was highlighted.

Chapter 3: Guiding Frameworks

This study was guided by decolonizing methodologies and a two-eyed seeing approach. These were appropriate guiding frameworks as I actively engaged the participating First Nations community in a respectful manner and I was attentive to their culture and environment. For the purposes of clarity, I will describe each approach separately; however, both approaches were integrated into the research process.

Decolonizing Methodologies

The rationale for using a decolonizing approach included a holistic appreciation of First Nations community members, their experiences and ways of learning/knowing, as well as it facilitated the ability to gain a meaningful and relevant outcome for the participating First Nation communities (Bartlett, Iwasaki, Gottlieb, Hall & Mannell, 2007). The First Nations People of Canada lay claim to a rich and broadly resilient history accounted with colonial policies and concepts that continuously undermine their sovereignty (Douglas, 2013; Kovach, 2009). The consideration of this collective experience and history is vital to reaching an understanding of the bearing that this can have on First Nations people's ordinary life and experiences (Bartlett et al., 2007; Denzin, Lincoln & Smith, 2009; Wilson, 2008). Western scientific traditions have customarily declined to engage this understanding or this aspect (Denzin, Lincoln & Smith, 2009; Smith, 2012).

To avoid this incongruity, Kovach (2009) noted that the function of decolonization is to create space for an Indigenous perspective without it being denied or ridiculed through either routine or intellectual society. Creation of this space is not about reclaiming dominion in research, but about centring concerns and worldviews that will result in the realization and understanding of research from the parties' perspectives and for their own purposes (Smith, 2012). The adherence to Indigenous worldviews or epistemologies is important for

comprehending the circumstances of their experience and the rationale behind their daily preferences within a contemporary context (Kovach, 2009). Recognition of these colonial impacts can also extend the possibility of transforming or seeking areas for change and thus, introduce this likelihood into the study spectrum (Bartlett et al., 2007; Kovach, 2009).

The roots of Indigenous epistemology lie in the significance of relations between all entities known on this earth (Adelson, 2000; Douglas, 2013; Wilson, 2008). Knowledge is built upon the relationships between things as opposed to on things themselves (Wilson, 2008). This contrasts with a Eurocentric worldview that looks to the individual as the entity which has control over the environment (Getty, 2010). The difference between these stances has led to an emerging movement by scholars to assert indigenous research paradigms based on their views and knowledge systems (Getty, 2010; Smith, 2012).

Enactment of a decolonizing methodology gives representation and say to the people under inquiry and positively shifts the balance of power in this research relationship to a more equitable standing (Kovach, 2009). The decision for recognizing First Nations community members' expertise on health and sociocultural issues will definitively increase the relevancy and benefits of this study (Bartlett et al., 2007). The advantages of securing a relationship with the community also include the anticipation for information previously unstudied and giving back the determination of any outcome that results from this study (Kovach, 2009, Wilson, 2008). Respect is maintained, as well, by aims to appropriately credit Indigenous knowledge to Indigenous peoples in publications and recognize the critical role that these members provide in decolonizing research through the entire process (Bartlett et al., 2007; Denzin, Lincoln & Smith, 2008).

It is important that discovery in this research is bi-directional with outcomes being useful to First Nations communities and researchers because this contributes to reciprocal capacity building and is a guiding principle of decolonizing methodologies (Bartlett et al., 2007). The fostering and building of a relationship based in research with a group that remains suspicious of contemporary research practices is crucial to the development of future advances in academia. This research aims to gain a decolonized perspective of the life stories and family caregivers' experiences when a family member required RRT. This type of orientation has the potential to reveal rich descriptions and contribute to the establishment of a culturally safe relationship between the researcher and the participant.

Two-eyed Seeing

The study was also guided by two-eyed seeing that: a) recognizes that there are diverse ways of understanding the world, b) acknowledges and respects the diverse ways of understanding, c) does not permit the dominance of one over the other, and d) develops a new understanding that lends itself to dealing with the issue under consideration (Hatcher, Bartlett, Marshall, & Marshall, 2009b; Martin, 2012). This approach brings Indigenous and Western ways of knowing together, for exploration and interdependency of the situation, by being conscientious to and utilizing the strengths and insights of each way of knowing (Bartlett, Marshall, & Marshall, 2012; Hatcher et al., 2009b; Iwama, Marshall, Marshall, & Bartlett, 2009; McKeon, 2012). This feature is the major guiding principle which supports aspects of both Western and Indigenous ways of knowing (Iwama et al., 2009; Latimer et al., 2014).

Indigenous health research must be attentive to both perspectives. Two-eyed seeing facilitates the researchers' abilities to move beyond the simple dichotomies of Indigenous knowledge and Western science (Getty, 2010; Martin, 2012). The conception of an innovative collective solution can be found using two-eyed seeing which prescribes a nurturing process

through an interaction and development of relationships or bridges between viewpoints (Hatcher, 2012; Hatcher & Bartlett, 2010; Hatcher, Bartlett, Marshall & Marshall, 2009a).

Two-eyed seeing offers a means to address discrepancies and provides an alternative lens to health research that embeds indigenous perspectives and realities within contemporary analysis (Iwama et al., 2009; Latimer et al., 2014; Martin, 2012). The framework maintains that one “eye” must not subsume or dominate the other but, rather, that the strengths and insights of each perspective must be considered (Bartlett et al., 2012; Hatcher, 2012; Hatcher & Bartlett, 2010; Hatcher et al., 2009a; Hatcher et al., 2009b). In her depiction, Hatcher (2012) reinforced that this approach accepts contradictory perceptions of the same event because each can be specific to the individual and such experiences can enhance the body of knowledge, so are appreciated and joined to it.

The dedicated health researcher must learn to see through both eyes, understanding that each eye represents a way to see the world that is always impartial because of the limitations and challenges that accompany any single approach to viewing the world (Iwama et al., 2009; Martin, 2012). In comparable portrayals, Getty (2010) and Hatcher (2012) determined that this conviction tasks us to understand the larger dimensions of our knowledge, not just physical and social but the spiritual and emotional as well, because each dimension of human understanding is necessary for a complete understanding of our world. The vision is that “when both eyes are used together, this does not mean that our view is now “complete and whole,” but a new way of seeing the world has been created – one that respects the differences that each can offer” (Martin, 2012, p. 31).

For this investigation, the descriptive qualitative approach is a method which circulated through interpretive exploration and was cultivated to health sciences research (Sandalowski, 2000; Speziale & Carpenter, 2007). The scientific virtue of applied qualitative health research

has been documented in historical records as well as scholarly literature (Thorne, 2008). Major principles of qualitative research are derived from traditional western methods and intrinsic to fostering knowledge (Braun & Clark, 2013; Simonds & Christopher, 2013). The incorporation of major principles and standards of western methods in research would strengthen and validate the study. Beside qualitative efforts, an alignment with the benchmarks of scientific rigor will yield a legitimate discernment of participant experiences that would be lost using empirical quantitative research (Braun & Clark, 2013; Lobiondo-Wood, Haber, Cameron & Singh, 2009).

The perspective gained by seeing through two eyes provides clarity and insight that help to fathom the health crises experienced across many Indigenous communities (Iwama et al., 2009; Latimer et al., 2014; Martin, 2012). In her speculation of theory, Getty (2010) concedes that any solutions must include their perspective and understanding about health and social issues to witness health improvements. Therefore, a Two-eyed seeing approach serves the needs of researchers and communities asking for participatory, community-based, action oriented research that reflect their needs, issues and concerns which could recommend solutions to some of the health ailments being experienced in First Nations populations.

Appropriateness of the Frameworks

An appropriate guiding framework for the study is a decolonizing approach, thus avoiding Western assumptions and connotations, to actively engage the participating First Nations community in a respectful manner, sensitive to their culture and environment. The framework will provide direction on the aspects of ESRD to be explored with family caregivers as they share their experiences. It provided a holistic, compassionate and engaging process for the researcher to understand the experiences and descriptions of persons who live in communities that harbor health disparities and the impact that these have on everyday life. It

guided the exploration and interpretation of the topic from the worldview of the people that it affects.

Two-eyed seeing has been cited in the journals of health research (Cameron, Carmargo Plazas, Salas, Bourque Bearskin, & Hungler, 2014; Latimer et al., 2014, Martin, 2012; Vukic, Gregory, & Martin-Misener, 2012), qualitative research (Carter, Lapum, Lavallee, & Schindel Martin, 2014), outdoor learning programs (Knapp, 2013), environmental justice (Schure et al, 2013), and increasing knowledge transfer and exchange in environmental studies (Bartlett et al., 2012; Hatcher, 2012; McKeon, 2012; Rich, 2012). Likewise, the framework has been utilized in engaging community based research between community members and university academics (Bartlett et al., 2012; Clark, 2014; Iwama et al., 2009). The method continues to be referenced in articles on science (Hatcher et al., 2009a), nursing education (Stansfield & Browne, 2013), the classroom environment (Hatcher et al., 2009b), and culture (Hatcher & Bartlett, 2010; Munroe, Borden, Orr, Toney, & Meader, 2013). Recommendations for approaches that are meaningful, respectful and reciprocal continue to cite two-eyed seeing as the process necessary to appropriately engage Aboriginal members (Battiste, 2010; Hatcher, 2012). As the principal investigator, I was guided by decolonizing methodologies and two-eyed seeing from the study's inception to completion.

Chapter Summary

In this chapter, two guiding frameworks were described: decolonizing methodologies and two-eyed seeing. The former approach facilitated the researcher's engagement with the participating FN community. It was used by the researcher to interact with community leaders and family members in a respectful manner, attentive to their culture and environment. The framework provided direction to the study as family members were invited to share their experiences with a family member requiring RRT. It provided a holistic, compassionate and

engaging process for the researcher to understand the experiences and descriptions of persons who live in remote communities. It guided a respectful and reciprocal exploration of the topic from the worldview of the people.

The second guiding framework was two-eyed seeing. This approach values the merits of Indigenous epistemology and Western science. Specifics of Western science will be provided in the next chapter.

Chapter Four: Research Method

This chapter describes the research design. I provide the rationale for using a qualitative descriptive method. Detailed information about the sampling technique, setting, recruitment, data collection and analysis procedures, and ethical considerations are provided. Strategies to achieve scientific rigor will be addressed.

A Descriptive Qualitative Study

Limited evidence exists about First Nations caregivers' experiences when a family member requires treatment for ESRD in rural or remote regions. To explore the experience of First Nations caregivers living in northern Manitoba, this study employed a descriptive qualitative method of inquiry guided by decolonizing methodologies and two-eyed seeing.

A descriptive qualitative study was warranted "given the range and possibilities evident in the qualitative research tradition, contextualized knowledge (such as Indigenous knowledge) can find an ally with these paradigms" (Kovach, 2009, p. 27). Descriptive qualitative research aims to uncover the reality of events by subjectively exploring the experiences from the standpoint of the participants thus making it an appropriate method of inquiry for this study.

Researchers conduct qualitative descriptive studies to remain close to the data, and to obtain straight, candid answers to events that are relevant to policymakers and clinicians (Sandelowski, 2000). While other qualitative methods aim to develop concepts and analyze data through reflective or interpretive interplay with existing theories, the effect of qualitative description is a depiction of participant experiences in words as close to their own as possible (Neergaard, Olesen, Andersen & Sondergaard, 2009). The common focus of the qualitative approach is the human being's experience, both as an individual and as it is shared with others (Braun & Clarke, 2013). A qualitative descriptive approach facilitates a rich description of how caregivers manage and care for a family member with ESRD and can generate theoretical

explanations for the way care is imparted among complex and diverse contexts (Leeman & Sandelowski, 2012). The evidence provided from understanding these experiences will aid nurses and other key stakeholders in imparting competent holistic care (Lobiondo-Wood et al., 2009).

Descriptive qualitative research requires the researcher to become immersed in the phenomena of interest so that an understanding comes from trying to grasp how others think, act, see, hear and feel (Munhall, 2012; Polit & Beck, 2012). Based upon my personal and professional background, I was well positioned to become further immersed in adult caregivers' experiences when a family member required RRT in a health care centre outside of the community.

Developing an understanding of the circumstances by actively listening to the narrative of the perspectives and experiences of the participants was required (Munhall, 2012). Cameron (2009) noted that the experience, style, intellect and creativity of the researcher remains a unique feature in qualitative studies. The researcher documents and analyzes the textual reports to discover the essence of the phenomenon by identifying individual and re-emerging common themes, and ultimately, reveals the identified, distinct and critical elements on items of interest (Creswell, 2007; Speziale & Carpenter, 2007).

The interpretation of data will be presented in a written report, by the researcher, to summarily describe First Nations caregivers' experiences when a family member requires RRT in The Pas, Manitoba. This description acknowledges the distinct experiences of the participants and will provide a depiction into the nature of caregiving when a family member requires treatment for ESRD. Descriptive qualitative inquiry guided by two-eyed seeing and decolonizing methodologies was an appropriate method for this research project.

Purposeful and Snowball Sampling

Qualitative research findings must have transferability to the population targeted for study (Lobiondo-Wood et al., 2009). The researcher ensured the sample was representative of the target population (Haber & Singh, 2009). Adult family caregivers were invited to participate with specific inclusion criteria to ensure that they represented and described their experiences of living with the phenomena under study. This study used purposeful and snowball sampling techniques. In purposeful sampling, the researcher consciously handpicks participants based on the researcher's knowledge of the population of interest, whereas snowball sampling takes advantage of the participants' social networks to locate future potential participants (Haber & Singh, 2009).

Inclusion criteria. To be eligible to participate in this study, the following criterion was established. Individuals were invited to participate if they: were 18 years of age or older, self-identified as a member of Misipawistik Cree Nation, had an immediate or extended family member with ESRD for one month or more, spoke and read English, and were able to provide a signed informed consent.

Sample size. In qualitative research, the size of the sample is not determined or known prior to the initiation of the study. The size of the sample is attained by the research method being used, and through the purpose and type of sampling; accordingly, scholars recommend about six participants (Haber & Singh, 2009). The total number of participants in the study was ascertained when data saturation was reached or when the researcher and thesis chair deem that the researcher had collected sufficient data to capture the essence of the caregivers' experience. As a general rule, "the researcher knows that saturation has been reached when the ideas surfacing in the dialogue have been previously heard from other participants" (Liehr, Lobiondo-

Wood & Cameron, 2009, p. 171). Recurring themes plus the lack of new experiences relayed by the participants, identified as data saturation, terminated recruitment efforts.

Research Setting

Participants were recruited from The Pas Dialysis Unit situated in The Pas Health Complex at The Pas, Manitoba. This unit provides RRT and renal health therapy to individuals and families from the Northern Health Region. To assist patients of First Nations descent, the Cree Nation Tribal Health Centre Inc. manages services and coordinates all aspects of primary health care delivery. Multidisciplinary health care teams provide renal health services, other therapies and outreach to the residents.

In this geographical region of Manitoba, all First Nations patients requiring RRT travel to The Pas Dialysis Unit on a thrice-weekly basis from their home community. The travel distance to access treatment may range from less than one kilometer to more than 250 kilometers (Appendix B). The Pas Health Complex incorporates a 72,000 km² geographical area and services a population of approximately 25,000 residents living in pristine wilderness and rural settings (HEM, 2014).

Misipawistik Cree Nation, formerly known as Grand Rapids First Nations, is a Cree community situated in northern Manitoba, on the shores of Lake Winnipeg, at the mouth of the Saskatchewan River (“Misipawistik Cree Nation”, 2017). There are approximately 868 members living on reserve with a median total income of \$16,368 per year and more than one third of the population is under 14 years of age (Statistics Canada, 2017). The estimated number of patients which accessed The Pas for CKD treatment ranged from five to eight individuals, with some variation as community members relocated, revisited or resettled in the region (Manitoba Renal Program, 2014). Coordinated efforts on behalf of all resources in the area are required to address the needs of patients with CKD and their family members.

Study Procedures

Following permission to access participants in the First Nations community and ethical approval from Education/Nursing Ethical Review Board at the University of Manitoba, The Pas Health Complex, and the Northern Health Region, recruitment began. A recruitment poster (Appendix C) was posted in the waiting rooms of the Dialysis Unit and the Cree Nation Tribal Health Centre Inc., inviting family members of an individual requiring RRT to contact the researcher. Recruitment posters were posted in the health authority office waiting room in Misipawistik Cree Nation. The researcher also requested local radio station time to describe the study and invite family members to participate using a recruitment script (Appendix D). A letter to Chief and Council (Appendix E) clarified the study purpose and nature.

When potential participants contacted the researcher, I arranged a one-hour, audio-recorded, face to face, one on one interview at a private location with a date and time that was mutually convenient. An ideal environment was one that allowed the participant and the researcher to be the only ones present during the interview process; however, allowances were made to accommodate the participant. Individual participant's homes or other private locations in the community were suggested as locations for interviews. Settings that provided a natural, private, safe, quiet and comfortable environment were chosen as it was recommended that an environment be sought to facilitate ease of interaction to minimize distractions and allow for confidential discussion to occur (Creswell, 2007; Lobiondo-Wood et al., 2009; Speziale & Carpenter, 2007).

Prior to conducting the interview, the researcher presented the participant with the consent form. The participant was provided with ample time to read the consent form and was invited to ask questions prior to signage. The participant was reminded that their participation was voluntary and that they could withdraw from the study or decide not to answer any questions

with no untoward consequences. Cultural aspects that may encompass respecting body space, seating choice and polite eye contact were considered. After the participant signed the consent form, a copy of the consent form was provided to the participant for their records. The researcher kept one copy in a separate file in a locked filing cabinet.

Data Collection Methods

Sources of data included a short demographic survey (Appendix G), verbatim transcripts collected from the semi-structured interview guide (Appendix H) along with a reflective journal about data collection and analysis.

Short demographic survey. After the consent form was signed, the researcher invited the participant to complete the form. The anonymous survey took approximately five minutes to complete and aided the researcher in describing the sample in general terms.

Semi-structured interviews. Open-ended, face to face, audio-recorded semi-structured interviews were the primary source of data. A semi-structured interview guide assisted the researcher in navigating through the interview process. Use of a guide ensured that rich data was collected. The semi-structured interview guide was informed by decolonizing methodologies and two-eyed seeing.

Researchers develop listening and critical reflecting skills that involve being open and perceptive when interpreting and judging the work of collecting data (Potts & Brown, 2005). An open-ended question was used when the researcher wanted the participants to respond in their own words or when the researcher could not anticipate all of the possible alternative responses (Whittemore, Grey & Singh, 2009). The use of this technique allowed the researcher to attain rich data through unobstructed dialogue with the participants who described the experience of having a family member requiring RRT on their own terms and in their own voice. Commonly used in nursing research, Whittemore, Grey and Singh (2009) explained that interviews are a

strong method for gathering information because they approach the task directly and have the ability to obtain information such as the participants' attitudes and beliefs. The advantage for this type of data collection include a higher response rate, the ability to clarify misunderstood questions, an observation of the level or type of understanding plus the allowance for richer and more complex data as the researcher explored participant responses (Whittemore et al., 2009).

The foundation of qualitative research lies in effective communication through the art of listening and with the aim of truly understanding the other (Munhall, 2012). Absolon and Willett (2005) found that recovering, accepting and becoming proud of who they are as they tell and retell their individual stories was a difficult challenge for Aboriginal peoples. Interviewers must therefore be prepared for strong emotions, such as anger, fear, or grief to surface as disclosures "bring it all back" (Lobiondo-Wood et al., 2009). It was the responsibility of the researcher to ensure that participants who undergo such emotions be provided with a means for reconciling these painful memories and feelings. In consideration of this potential emotional distress, each participant was provided with the contact name and information of a professional mental health counselor in the region. In the event that the researcher identified that the participant was experiencing emotional distress, the researcher asked if they would like to take a break or if they would prefer that the interview ceases. The researcher provided the participant with a fresh glass of water and tissue. When the interview was completed or deemed to be "over" by the participant, the researcher provided a "thank you card" and a \$25 honorarium.

Reflective journal. A journal documenting the thoughts and feelings of the researcher was kept as a tool to assist in data collection and analysis as well as an ongoing record of study occurrences. Cohen and Cameron (2009) characterize qualitative researchers as frequently writing journals during their research activity so as to monitor and become aware of personal biases and feelings. The relationships and interaction between researchers and participants, the

influence of each in the knowledge produced in the study plus reflections on the actions and observations in the field are important to the research process (Munhall, 2012). Maintaining the practices and methods that imbue accurate representations of the people being consulted is essential to valid and respectful research (Smith, 2012).

Decolonizing methodologies challenges researchers to examine research motives, values, beliefs, and methods through questioning, reflecting, and acknowledging their locations (Absolon & Willett, 2005). Defined as reflexivity, researchers must recognize that they are an integral part of the research, become aware of their own assumptions and concede how their interpretations of these observations can influence the results of the study (Lobiondo-Wood et al., 2009; Munhall, 2012).

Member checks. During the interview, and again at its conclusion, the researcher asked the participant to clarify particular statements for accuracy. The participant was also given the opportunity to add to the interview with a final question that asks “is there anything else that you would like to add?”

Participants were provided with copies of their de-identified transcripts so that they could verify the accuracy of the content and statements. This process secured accuracy of their descriptions of caregiving for a family member who required RRT. This method of validating the credibility of qualitative data through evaluations and discussions is defined as member checking (Polit & Beck, 2012).

Ethical Considerations

Ethical approval of the study was obtained from Education/Nursing Ethical Review Board at the University of Manitoba and The Pas Health Complex before commencement of the study. Although unprincipled research can occur in any environment, the potential for ethical infringement within this First Nation community was compounded by its small population

(Kovach, 2009). The possibility of potential repercussions to the participants emphasized the significance of securing confidentiality and anonymity during each step of the research process. Participants were protected through the adherence of the principals of the Tri-Council Policy Statement regarding research with First Nations, Métis and Inuit Peoples of Canada (CIHI, NSERC, & SSHRC, 2010). Prior to disseminating the study's findings, I will seek permission from the Chief and Council.

Confidentiality

Participants had the right to expect that any data they provided was kept in strict confidence and that their privacy was protected at all times (Polit & Beck, 2012). This required a number of precautions to ensure that a breach of confidentiality did not occur, which entailed some careful interventions. Because of the small size of the community, to protect confidentiality, I used pseudonyms, limited access to data and records, secured records, and changed small facts when writing the results of the study to protect disclosure of participants' identities may have placed them at risk (Munhall, 2012).

All data were de-identified and stored on a password protected computer system (S: drive at the University of Manitoba) only accessible to the researcher and the thesis supervisor). Hard copies of the consent forms and honorarium receipts were kept in separate files in a locked filing cabinet in the home office of the researcher. The transcriptionist was required to sign an oath of confidentiality and only the researcher and research supervisor had access to de-identified transcripts, the diary of the community member, and reflective journal.

Anonymity

Assuring the anonymity of study participants necessitated the protection of their identities (Haber & Singh, 2009; Polit & Beck, 2012). Anonymity is seen to occur when the researcher cannot link participants with the information provided (Polit & Beck, 2012).

Data Analysis

Demographic Data

A short, demographic questionnaire requesting demographic data was used to acquire general descriptive information from participants. Although they seem to have a less prominence in qualitative research, numbers are an integral part of the data, and employing statistical skill is essential to good qualitative research (Sandelowski, 2001). Percentages, ranges and averages were used to describe the sample (age, gender, number of family members residing in the home, relationship to the family member requiring RRT, and distance in kilometers between the family home and the dialysis unit).

Analysis of the Textual Data

Interviews were transcribed verbatim by a transcriptionist experienced and adept at the process that requires one to be cognizant of urgent deadlines and initiation of data analysis in the research process. Qualitative data analysis is an active process that occurs simultaneously and continuously with collection of the data, typically in a deliberate, careful, and studious fashion (Polit & Beck, 2012). Transcripts, and reflective journal entries included line numbers, numbered pages, cover page with date, time and location of the interview, and the assigned code name of the participant. The researcher reviewed the audio recording and related it to the transcript to ensure accuracy.

Data analysis began with preparing and organizing the data for analysis, then classifying and indexing the data, and finally representing the data in a conclusive format that integrates the data as a unified whole (Creswell, 2007; Polit & Beck, 2012). The challenge for researchers involves preserving the intrinsic nature of the participant's experience while performing a comprehensive analysis that breaks down the data into smaller portions.

Transcripts, and reflective journals were read and reread, then analyzed for recurring words or key statements. I focused on the Indigenous meaning and representation of constructs such as coping, healing, stress or anxiety, as described by participants, and tried to diminish the use of terms that may culturally and contextually lack the implications vital to First Nations populations (Bartlett et al., 2007). Key statements were transferred to index cards with the key words or codes written on the front of the card.

A clustering process followed this initial content analysis and coding of key statements. The researcher began data analysis with the first collection of notes and continued on until satisfactory interpretation was accomplished. The process of data analysis in qualitative research traditions necessitated several stages of data reduction, data display, plus drawing conclusions and verification (Lobiondo-Wood et al., 2009).

Essential themes or aspects of an experience were uncovered from participants' descriptions of the experience through a detailed approach. Making meaning with Indigenous inquiry involves observation, active emotion, contextual knowledge, recognition of patterns, and reclaiming of tribal interpretations (Kovach, 2009). Thematic statements were highlighted and then reduced into essential and incidental themes using free imaginative variation. This offered further insight into the themes that identified what it means for participants to care for a family member that requires RRT.

Returning to the original account in each key statement resolved doubts about the context of statements or the accuracy of coding. The challenge was to understand the experience of being a First Nations caregiver when an individual in the family had a chronic disease requiring regular treatments. Presentation of findings that are consistent with Indigenous inquiry holds much promise at bringing Indigenous epistemologies into research (Kovach, 2009). The central themes that are revealed exhibited the unique ways in which the First Nation caregiver experienced the

phenomena. These findings will be used to inform policies and interventions regarding family health promotion and CKD management in First Nations communities.

Methodological Rigor

The capacity to rely on the findings of this study and consider them as valid unbiased representations of the participant experience was derived through the trustworthiness or believability of the study findings, referred to as rigor. Davies and Dodd (2002) identified rigor as the unspoken standard by which all research is measured and the authoritative evaluation of good research. Rigor is ascertained through measures that include: credibility, dependability, confirmability and transferability.

In qualitative research, findings need to be transferable to other similar groups or populations so rigor is a major concern (Lobiondo-Wood et al., 2009). Lincoln and Guba (1985) proposed that credibility refers to prolonged engagement or confidence in the data ensuing with interpretations of consequence (Munhall, 2012; Polit & Beck, 2012). Varying activities such as continuous or repeated engagement with the data, member checking, and verification of meanings with participants during interviews secured credibility. Evidence and credibility are so closely aligned within research that the degrees to which a research framework identifies and follows the procedures for a specific methodology remain influential factors for determining them (Kovach, 2009). Frequent member checks and verification of meanings with participants supported findings and strengthened the accuracy of the researcher's interpretations. Data triangulation (transcripts, the demographic questionnaire and reflective journal added to the rigor.

Outlining the decision-making processes during data analysis ensured transparency and added to the dependability. A study must be dependable over time and conditions so as to form the basis of further research, practice, and theory development which indicates reliability or

stability in the data (Lobiondo-Wood et al., 2009; Polit & Beck, 2012). A continuous data trail consisting of reflective journal notes, verbatim transcripts including margin notations and documentation of emerging concepts or themes was provided to the research supervisor. The research supervisor, who has expertise in qualitative research with Indigenous populations, analyzed key transcripts and compared and contrasted emerging codes, categories, and themes with the researcher.

Polit and Beck (2012) define confirmability as the criterion for integrity in qualitative inquiry that refers to the objectivity or neutrality of data and interpretations. The extent that findings were derived from repeated and direct evidence of participants and documents, as opposed to potential researcher bias, is deemed confirmability in research (Munhall, 2012; Polit & Beck, 2012). The documentation provided a trail that maps the findings back to the data sources. This process demonstrated the ongoing reflection and scrutiny required to confirm that the interpretations were valid and based on the data.

The reflective journal served as a record of reflexivity in this study. Researchers must challenge themselves to understand how their perspective may be shaping the processes in qualitative research so that these effects can be minimized (Lobiondo-Wood et al., 2009). The journaling of researcher perceptions plus decisions made concurrently provided a record of these developments during the study.

The applicability or extent to which qualitative findings have meaning to others in similar contexts is designated as transferability (Lobiondo-Wood et al., 2009; Munhall, 2012; Polit & Beck, 2012). Describing the caregivers' experiences using their own words facilitated transferability to other First Nations caregivers in similar contexts.

Chapter Summary

This chapter described the research method used. A qualitative descriptive approach was employed to answer the research question. Information on the sampling technique, setting, data collection and analysis procedures, and ethical considerations was provided. The chapter also included a detailed description of strategies to achieve scientific rigor.

Chapter Five: Findings

This chapter provides a general description of the sample of Misipawistik Cree Nation caregivers of a family member requiring RRT in The Pas, Manitoba. A summary of the sample characteristics is followed by the findings with a major theme and subthemes.

Description of the Sample

In this section, I provide a summary of results from the short demographic surveys. Eight Misipawistik Cree Nation caregivers volunteered to participate in this study. Four participants were females and four were males. Their ages ranged between 37 to 59 years with a mean age of 49 years. Participants had seven to 16 years of experience as a caregiver to a family member requiring RRT.

The majority of participants (75%, 6/8) were married. All participants were either employed full-time or seasonally employed. Most participants reported that their highest level of education was high school and several participants had a university level education. Participants rated their understanding of ESRD and RRT as adequate.

Half of the participants resided in the same home as the family member requiring RRT. The other half resided in a separate household within close proximity to the family member requiring RRT. Participants commonly resided in three or four bedroom houses with four to six other persons spanning three generations. Participants were either the spouse or the child of the family member requiring RRT. Each participant was directly involved with the daily care of the family member requiring RRT and five participants were the primary source of family income.

The distance from their homes to the nearest health centre was reported as one to four kilometers, which contrasted with the geographical distance from the community to the nearest hemodialysis unit which was estimated by participants at 200 – 300 kilometers. Participants shared that they rarely accompanied the family member on route to, during, and from RRT.

Major Theme: Resilience

Participants described a substantial quantity and quality of care and concern for the family member requiring RRT in The Pas, Manitoba. Participants were devoted to the family member requiring RRT and experienced ongoing concern for their wellbeing. Participants described how they applied considerable energy towards the care of the family member requiring RRT in conditions which necessitated resilience. Resilience was symbolised in distinctive forms and events.

The major theme of resilience was comprised of several subthemes. Participants conveyed a resilient devotion to the care of the family member requiring RRT subsequent to Miyopimatisiun (Cree way of life) which prompted relations with Indigenous and non-Indigenous contexts in their hunt for knowledge and resources that would strengthen principal aspects of care and support.

Resilience and The Blue Bear Vision

Decolonizing methodologies and two-eyed seeing ensured that I chronicled a significant moment that occurred during data analysis. I experienced a dream or vision during a meeting with my supervisor. It was a moment of astonishment for me since the vision or recall came, not while in ceremony, but during a visit to the supervisor's office. The vision was extremely vivid but its meaning was initially unclear. Its meaning eventually came into focus.

At the time of the vision, the research supervisor and I were discussing future plans and a notation was being posted on the calendar. Then, the vision came back like a moment of "déjà vu" where the time and place were felt and seen as familiar. I recalled dreaming about a bear standing behind the research supervisor and clutching her shoulder like a cherished relative. The similarities between the dream and that moment were prophetic and considerably spiritual. In the recollection of the dream which could now be dubbed a vision, the Bear was the colour of royal

blue and the effect projected the animal as a glowing or electrifying manifestation. The detail which captured my attention was the expression of tender love and affection on the part of the bear, much like the face of a mother yet it was still a bear.

In First Nations culture, the bear holds a place of high prestige and symbolizes honourable attributes in life as well as family such as the sacred teaching of courage or in the emblem as The Bear Clan. In a similar fashion, the colour blue has been known to represent loyalty in western culture and is traditionally worn by brides at weddings as a promise towards this value. In the vision, the bear radiated the colour blue like an energetic light that emanated from the body which glowed blue and the effect gave the impression that the bear was electric blue or was energized with blue electricity. This vision was shared with the research supervisor who advised me to immediately document the recollection of the entire dream in my reflective journal.

After documenting the dream and the recollection of the vision, I determined that the bear symbolized First Nation caregivers' experiences. The main proponent, the bear, represented the participants of this study who were faithful, strong and loyal beings that used their energy, symbolized through the blue electricity, to care for their family and live a Cree lifestyle or Miyopimatisiun. In this circumstance, the exceptional meaning of the vision emerged when an expression of caring was noted in the bear hugging the research supervisor in a gesture of love. Furthermore, there was the confidence displayed by the bear indicating the inclination to wait for understanding in the observer, and the unique insight gained from this attainment. A compelling factor to this spiritual account was conveyed with the sharing of knowledge and the intensity of the vision surfacing in an educational institution inferring that this study was an apt and fitting pursuit. It signified to me that good or positive consequences will happen. As a serendipitous concurrence, Jordan River Anderson's favourite color was blue and the logo for Jordan's

principle uses a drawing of a blue bear (First Nations Child and Family Caring Society of Canada [FNCFCSC], 2018).

The following is a list of the subthemes that will be presented and which were detailed by the participants and symbolized through the Blue Bear:

1. Blue Bear is devoted: Care of the family member requiring RRT.
 - a. Housing
 - b. Transportation
 - c. Food
 - d. Mental health
2. Blue Bear is Miyopimatisiun: Cree lifestyle to care for the family member requiring RRT.
 - a. Cree food
 - b. Warmth
 - c. Physical ability
3. Blue Bear is home: Relations with Indigenous agencies.
 - a. Family
 - b. Elders
 - c. Community members
 - d. Community services
4. Blue Bear is away from home: Relations with non-Indigenous agencies.
 - a. Dialysis
 - b. Medical appointments
 - c. Therapy initiation
 - d. Kidney transplant
5. Blue Bear is hunting knowledge: Resilience in a remote community.
 - a. Gaining information
 - b. Establishing rapport
 - c. Confirming historical records
 - d. Seeking interpretations
 - e. Preventing loss

Blue Bear is Devoted: Care of the Family Member Requiring RRT

This section presents a detailed description of various areas that the participants' prioritized in the care of a family member requiring RRT. Instead of providing a succinct or

concise definition of CKD, many participants found it easier to describe the activities which were believed necessary for the care of their family member and the way they incorporated these activities into their daily lives. As a means to reduce or alleviate their concern for the family member requiring RRT, participants devoted their attention to four major areas of care. Over the passage of time, it was routine of participants to assist in housing, transportation, food and mental health aspects which conform to the management of ESRD. To help clarify the findings, significant quotes are supplied using fictitious names.

Housing. Most participants related that housing was sub-standard to the health care needs of the family member requiring RRT. Several participants offered a tour of the house in which the family member lived to observe needed doors and areas infested with mould. Slight adjustments to the house, like ramps or equipment in the bathroom, were provisions to support safe mobility but the assistive devices had sporadic maintenance or inspection measures. Four participants lived in the same house with the family member requiring RRT and were tasked at providing 24/7 care. The other four participants lived in a different house and contributed to regular cleaning of the house. All participants talked about the risk of infection for the family member requiring RRT. As well, keeping the house secured when the family member was away in The Pas was problematic as medical transportation schedules were public information.

You know she lives in a house, to me, that place is condemned you know. It`s not livable, I think, for an elder. I wish they would give her another place, you know, or somewhere, something a lot better, something, you know, like where she can have a bath and everything. (Riel)

Actually she had a few break-in`s too.....kids, `cause they know she`s gone, right. (Kathleen)

Transportation. The regular commute between the community and the treatment facility for the family member requiring RRT placed transportation as an area of concern. Participants

conversed about the length of transit, the vehicle transporting the group, the discernment of the drivers, the condition of the highway and the fluctuation in environmental factors.

Well I worry about him, like the time he travels in winter, its blowing snow and all that, sometimes he has to stay in The Pas, he can't come home. (Barry)

Participants also provided transportation for their family member since attending to their wellbeing entailed annual check-ups, diagnostic procedures, and emergent transplant opportunities through travelling to urban health centres. Supporting the family member at these critical events was important to participants; however, financial constraints or occupational duties frequently were cited as factors that prevented them from attending these important medical appointments.

The band, the band gives like \$200, that's for rooms and meals, but that doesn't really help at all like 'cause the gas and you know the room is like over \$100/night and \$200, that's not, when you need to eat, yeah. It's not much. (McKayla)

Food. All participants regarded food as an aspect that they could help with but only two participants actively guided the family member in an appropriate diet for ESRD. The preparation, collection and sharing of food allowed members within the family and community to support and monitor the family member requiring RRT. Some participants enhanced their knowledge about diet while others expressed concern over the ability to provide the proper nutrition to their family member. The acquisition of fresh food for the family member took both effort and expense. It was apparent that food brought pleasure and togetherness to the participants and their family members. In one instance, the benefits of adhering to the family member's diet was worth a jibe by the participant.

Well I check on . . . from time to time, make sure she's eating, eating healthy. Well I go check her fridge or sometimes I'll go with her to the store to buy healthy foods. (Kathleen)

Well I make sure that she eats good. The stuff that she`s not supposed to eat I, I warn her sometimes too like when she eats, especially with the salt hey, `cause I know that salt is bad and even the fruit, like the bananas are high in potassium, so I make sure she doesn`t, she tries to sneak them but I don`t let her (chuckle), I don`t let her. (McKayla)

Mental health. Providing activities that ensured the happiness of the family member requiring RRT was vital. Participants provided amusements such as computer games, playing slots, cultural events, land-based activities and comical moments to brighten the mental health of their family member requiring RRT. As well, the participants found that children and youth would trigger immense enjoyment and optimism on the part of the family member and they actively encouraged this interaction. During the discussions, some participants acknowledged being sensitive to the emotions and statements that would be disclosed by the family member. Participants observed that the possibility of depression in the family member was amplified as the days passed and more time was focussed on going to treatment rather than being home and engaging with family. Conversely, the intent of the participants to provide holidays or vacations for the family member requiring RRT had been met with such complexity that it would be necessary to abandon these notions.

Yeah, she struggles with that, I know that, yeah because I seen her get really depressed sometimes, but she says her family, that`s the only reason why she keeps going is because her family, she wants to see them grow up yeah. And I tell her that too hey, whenever she`s feeling down I`ll, I`ll inbox her a picture of the kids. (McKayla)

And I see then, I seen a lot of them died already, passed away and I`ve tried to get her going to, so she doesn`t give up `cause I think when they give up on life that`s when they, they have nothing to live for. (Martha)

Like my kids tried it one time and we were going to go and they phoned this place that they were going to take us in Las Vegas and it would have cost her so much to get that dialysis out there.

(Patrick)

Blue Bear is Miyopimatisiun: Cree Lifestyle to Care for the Family Member Requiring RRT

Participants associated the activities and devotion to living with a family member requiring RRT as part of typical daily life. This attention to housing, transportation, food and mental health aspects similarly aligned with the traditional practices of food, warmth and physical activity that stem from the Cree way of life expressed as Miyopimatisiun. Cree food, warmth and physical activity were discussed by the participants as significant to the care of the family member requiring RRT.

Cree food. A preference for Cree food by the family member requiring RRT was expressed by participants as the central motivation behind acquiring or purchasing game such as fish, moose and wild birds. Some participants believed that Cree food would be more appetising and therefore, beneficial to the family member. Grocery excursions were a regular occurrence for participants and food was costly. To provide adequate nutrition, participants situated an added reliance on traditional Cree foods that the family member requiring RRT would like but were difficult to obtain. Cree food was perceived as sustenance to the wellbeing of the family member requiring RRT, and the pleasure of eating it also helped to boost their spirit.

Yeah, and that`s what we eat, moose meat, like it`s good. We make hamburger, like we make it ourselves, my partner makes hamburger with that moose meat and it just lasts us and its good, like it`s healthy, it`s good for her and pickerel, but I have to buy it hey, I buy it off people.

(McKayla)

By far, the favourite aspect of Cree food for the participants was the preparation and cooking of the food and food products for the family member requiring RRT. Many participants talked about the preparation or organization of meals for the family member and exhibited delight at providing traditional food. Participants expressed that they held more trust in Cree food than processed food. Thus, the participants wished that food guides would include Cree foods pertinent to the care of their family member requiring RRT.

So I cook her moose meat and I cook her ducks, whatchamacallit, Erin came and gave us two ducks, so I roasted them right away, she liked that. (Curtis)

Yeah, yeah, like someone to come and show us, like, what`s good stuff to eat. Yeah, like healthy stuff `cause I don`t, like, like I said hey, it`s like wild food mostly I cook for my beloved, yeah, yeah. (McKayla)

Warmth. Participants shared their concern about the family member requiring RRT feeling cold. Aspiring to keep their family member warm and comfortable, participants described how they fussed about transportation, housing, and the effects of the cold climate. Being situated in a northern locality, participants experienced weather changes such as rain and snow which diminished highway travel. Participants expounded on how they were concerned about keeping the house warm. This concern about heat occurred along with a perception that sanitation of the house was imperative because the family member requiring RRT needed to be clean to be ready for treatment each week. However, despite steadfast care, participants suspected that incidences of heating dilemmas, mold, wear and contamination in the home contributed to the chances of infection or illness in their family member. Collectively, all the participants were familiar with the weekly medical transportation schedule of the family member requiring RRT and exhibited a disposition for upholding warmth in transit and at home.

It was cut off and, and I talked for myself. I phoned the Hydro and I explained to them, I'm the only one working I said and my relative is on dialysis and I said we can't be without a phone, we need a phone in our house and we need the waterworks in order for us to be clean and everything. So they put it back on, I had to make conditions with them. (Martha)

The roads get icy in the wintertime and traveling and trucks, just the blowing snow everywhere and that. I get worried about them. (Riel)

Physical ability. Each participant reported an inclination to be physically active and several retained employment plus attended to other family members and the family member requiring RRT. Many participants described their capability at caring or attending to family in all major areas (housing, transportation, food, and mental health) and included the family member requiring RRT in these responsibilities. Their days were loaded with activities and tasks which obliged participants to anticipate early mornings and late nights. Yet, participants expressed little disfavour, but rather more eagerness to perform tasks that demanded continuous physical abilities in living with or caring for a family member requiring RRT.

If I'm not working outside on the land, I'm fishing, commercial fishing, and if I'm not commercial fishing, I'm doing something outside, like the yard, cleaning the yard . . . stuff like that. (Riel)

Blue Bear is Home: Relations with Indigenous Agencies

The desire to keep the family member requiring RRT in the community and among family was the goal. Connections to place, land, and community (family, Elders, community services) were important to participants.

Family. Participants were long standing residents of the community with considerable ties to the community through a broad network of familial relationships. Participants disclosed that several generations of their family lived in the community, typically in close proximity to

each other and this permitted them to support one another. Participants stated that they looked to immediate family and then extended family for support when a situation arose regarding the family member requiring RRT when they were strained or challenged to provide support. In circumstances which advanced outside the family, participants dispatched inquiries in caring for the family member requiring RRT to elders and other community members.

She doesn't want to be a burden to anybody in other words, that's how she, my mother is. But when she goes somewhere, she'll either go to my sister Edna's, or my brother Tony or my brother Calvin. She doesn't go to Abigail's hardly. Cause Abigail comes here hey. Yeah she just walks over. She comes here when mom's home, she bakes bannock for my mom when she needs bannock. (Curtis)

And then when, sometimes I help her, take her to the, to her medical appointments, like me and my sister take turns, so there's only two of us that actually take her. (Kathleen)

Elders. Participants shared that they consulted elders for wisdom in determining the best method to care for the family member requiring RRT. The participants recalled that elders were visited with questions about family and community history. Elders and family members requiring RRT were frequently contacted with invitations to gatherings and functions where they were afforded great comfort and respect.

And sometimes she misses those things they put up for ladies like they have elders tea, they usually have those...on Mondays or...yeah or Wednesdays, she misses them. (Tricia)

Community members. Several participants admitted that they consented to participate in the study due to the advice of another community member. Participants exhibited regard for members of the community that petitioned into the care of the family member requiring RRT.

Yeah, Noreen comes around or Celia, usually it's Noreen most of the time because she goes around taking care of all the other elders. (Patrick)

Yeah, 'cause she does like to do lots of stuff, she likes to go out, like some of the ladies take her out to go hunting and she wants to go fishing. (Tricia)

Community services. Providers working in local health services were perceived as advocates in covering caregiving and medical expenses. Participants related that requests beyond sanctioned disbursements were unlikely to be granted and were a constant source of frustration. In spite of these sentiments, regular engagement with people that worked with in a variety of services in the community occurred with all participants. Some participants appeared to enjoy the interaction.

The band and health authority, so she gets from both places 'cause what the health medical services reimburses is not enough to travel there and back. (Kathleen)

I don't think so, it's not enough 'cause of the prices of everything nowadays and you have to, and plus they, well they feed us in the hotel there but going that far and staying for a couple of days, it would be little more than \$200, that's for sure. (Riel)

Blue Bear is Away from Home: Relations with Non-Indigenous Agencies

Accessing health care was predominant in the stories of the participants caring for a family member requiring RRT. Several spent considerable time in health care settings interacting with a range of health care providers. Caregiving for a family member requiring RRT led to diverse relations with non-Indigenous agencies. The care for the family member requiring RRT was especially challenging to participants when their family member was off-reserve to access hemodialysis, medical appointments, therapy initiation and renal transplant.

Hemodialysis. All of the participants recalled going with the family member requiring RRT to treatment. Situated in The Pas, the participants reported that they were comfortable with going into the dialysis unit but hesitated attending health facilities in other locales. The health care providers at dialysis were friendly and allowed their children to visit the family member

requiring RRT. In rare incidents, the family member requiring RRT had problems with a health care provider in the unit, but the matter was ultimately resolved. Some participants admitted to going as often as they could to the dialysis unit with the family member requiring RRT, when work and other responsibilities did not intrude. Alternately, there were a couple of participants who disclosed feeling overwhelmed by the entire unit plus the treatment procedure and preferred not to attend dialysis.

She says she never has no problems with the nurses, every time she needs, she needs something she, she's you know she's getting it, like there used to be one odd person there that, but she left.

(Patrick)

I don't know, maybe because, I don't know 'cause some, some kids will just run around and touch everything, right. Maybe, but these ones will just go stand around . . . they will ask her questions. But they're (dialysis unit) really good with them. (McKayla)

Medical appointments. During trips for health-related appointments, it was noted that overnight stays were sponsored by participants or the family member requiring RRT. To reduce expenses, day trips were frequent and necessary occurrences to participants with family members requiring RRT. Furthermore, trips to the major urban centre were often shortened by their own desire to return to the security of home and community. Participants dreaded taking the family member to treatment on medical trips and regularly encountered micro-aggressions or hostility within the health care system. More specifically, a lack of courtesy from health care providers was reported by participants who escorted family members requiring RRT to medical appointments in southern areas.

As they travelled on medical trips, participants spoke of using these times to purchase necessities as well as attend to the family member requiring RRT at health appointments. On other occasions, the participants balked at escorting the family member, citing conflicting

responsibilities or lacking resources for the journey. Discrepancies between health care regions was described as confusing.

Yeah, it is yeah, but sometimes there's nobody else to take her and we have to work, when we have to fish and that me and Manny will just go like a day trip and come right back. (Tricia)

Yeah, right in the hospital, there's different centres, I think there's like three different places where she goes. Yeah, and it depends where there's one available, that's where they'll send her.

Yeah, but they're just, like they're rude and unfriendly, hey, like I seen it a few times too and she doesn't like going for dialysis there, she just, she dreads it. (McKayla)

Therapy initiation. Few of the participants were able to recall being informed about ESRD and RRT. Adhering to a rigorous schedule and the requirements of treatment which was offered at a distant location was onerous. At the onset, participants were disturbed to realize that life with the family member was regimented.

Even when, we have a friend and we went, we go visit them and when she was telling when they were sending her to Winnipeg for, the names of the doctors, we knew what was coming to her, we told her and she said, no it's not, it's just that they're doing, I said you know I said it's a stage that we went, seeing those different ones and finally we got to that place where they put in that thing. (Martha)

All of a sudden, yeah all of a sudden, we just, she just said that she has to start dialysis. (Kathleen)

Now we can't. We used to take family trips, yeah. But then you know, we don't want to leave her either 'cause well we just don't want to leave her, like you know, we'd rather her to come with us but she can't because she has to have it every third day. (McKayla)

Kidney transplant. When the participants spoke about the possibility of a kidney transplant for the family member requiring RRT, they related being extremely excited at first and

thought their family member would soon acquire a donor kidney. Several participants discussed these experiences that resulted in several living donors and transplant attempts. It was a subject that brought the participants some degree of regret or sadness while they described the emergent calls and rush to the city. They perceived that the next donor offered their kidney and subsequently changed their decision. This was an area of speculation because the participants never knew or comprehended what exactly transpired when the donation or the transplant was unsuccessful.

Well, they tell us they have a kidney for her and then, and we have to be prepared to go there within 16 hours, so yeah they call us and then we go and then go straight to the hospital and they'll set her up, yeah...Actually the donor for those kidneys was, I don't know what the doctor said but something about their, having them live a little longer than expected on a machine and then their organs, start to be no good or something like that and then the kidneys are no good, so that's twice that happened to her. (Tricia)

And then, and then her mom told her not to, she said, they're trying to use you for your body organs. (Martha)

Blue Bear is Hunting Knowledge: Resilience in a Remote Community

Participants considered their knowledge of CKD as adequate. This comprehension reflected the motivation of participants to learn about CKD for the optimal care of the family member requiring RRT, which was constructed from the limited resources provided to them. Participants described gaining information, establishing rapport, confirming historical records, seeking interpretations, and preventing loss as behaviours which would magnify resilience in a remote community.

Gaining information. Participants displayed an urge for gaining knowledge and information that would support their family member requiring RRT but disclosed perceptions

that they were being overlooked, disregarded, and ignored by health care providers. This meant that participants would have to search other avenues to augment their own knowledge and information about CKD such as books, brochures, websites and conferences. Some examples of questions that participants wanted to ask were: Who do I ask when I need to cover or protect the access site? Is the family member allowed to eat Saskatoons? Is fried bannock better than baked bannock for my family member? Can the family member go camping? Can they go swimming? What do we need to know to keep the family member safe during activities like swimming or camping?

And the one I spoke about, I said no I want her to go to The Pas, and the doctor said, I'm not talking to you, I'm talking to her. (Martha)

He inboxed me a bunch of information with them about my mother's, what, what, what not to give and stuff hey. (Riel)

Establishing rapport. In a hospital setting, the ability to escort the family member and establish rapport with health care providers varied among the participants. Some participants obtained information through trusted resources in the community. Other participants reported that they were nervous to ask for information from health care providers since it would be provided in a manner that was perplexing to them. Similar to this apprehension, a few participants elected to avoid all exchanges with health care providers even if an opportunity presented itself. In most cases, communication between families and health care providers was generally conducted through indirect dispatches or third parties.

It's been bothering her for two, three weeks and we kept telling them to tell the doctor, the doctor had to know. And then when, when it (a cardiac incident) happened, the doctor's rushing around now. How come he didn't rush around before, before it happened, you could have, I don't know if they can prevent that but they could have gave her something to, so it didn't happen. (Curtis)

But it would be good if somebody in town would go check on their feet once in a while you know. Because when she broke her toe that time she didn't even know it was broken. Yeah for a long time she didn't even know. But if somebody was going around and looking after their feet, like to check their feet once in a while, like the nurses, maybe it would have prevented it, you know what I mean. (McKayla)

Shaping an explanatory framework of ESRD. In the reflective journal, I documented how some community members interpreted that CKD and ESRD were consequences of impure water that contaminates and clogs the kidneys. Traditional medicine such as red willow bark was required to clear the clogged kidneys and purify the system.

Participants shared that there had been other individuals in the community with ESRD who required RRT. Confirming the historical records of community members requiring RRT was a channel that the participants were able to follow to acquire knowledge from Indigenous persons. Participants sought out respective experiences from other community members and eagerly elaborated on the wisdom they were provided about living with a family member requiring RRT. Individuals shared these experiences, noted the participants, so that other community members would not have to suffer a similar fate. Eventually, these dialogues at confirming historical records, between the participants and community members, evolved into the causes of kidney disease and the methods which would prevent symptoms from occurring in the family member requiring RRT.

Yeah, Yeah I knew what, but they've been doing the same thing and then I never thought I'd be doing the same thing that my brother-in-law did to my sister-in-law 'cause they used to go with her, we used to go with them, now I did that. (Patrick)

He got sick and that was it. Yeah . . . came home one year at Christmas and he got sick and just passed away 'cause he was on dialysis, too. He got an infection and they couldn't heal him.

(Tricia)

Seeking interpretations. Participants studied the knowledge they collected and determined which aspects improved wellbeing and thus enhance the life of the family member requiring RRT. This process of seeking interpretations from lessons or scenarios heard through relations with people in the region was offered by participants as novel insight. There were suggestions that restricting the consumption of additives, eating only wild meat, limiting processed food, and playing with children would enrich and prolong the life of the family member requiring RRT. Furthermore, the participants described contentions from other caregivers about having lived a hard life, and the difficulty in giving proper care. Key information was perceived to be suppressed, and other caregivers reported feeling marginal to the decisions on health and wellbeing.

They don't believe it and then some even will say to her, well how come those other ones look dark, they turn dark, like you know what I mean. But she knows because you don't use lots of salt. (Martha)

Another thing, if you're a diabetic, you just got to watch yourself when you have diabetes, you have to take your pills whatever, but dialysis is different because your kidneys are already failed. It would be different if you had one kidney, you wouldn't have to go on dialysis, but once the kidneys fail, that's why you have dialysis, that's how I understand it. (Curtis)

Preventing loss. In hushed or whispered tones of voice, participants occasionally alluded to the chance that their family member requiring RRT would succumb to ESRD. It was a great fear. Participants noted that few individuals requiring RRT survived very long when they were required to relocate for treatment at urban centres. Towards this conviction of preventing loss,

participants searched for information and knowledge which would strengthen and extend the life of the family member requiring RRT, with an obvious determination to fortify this resilience.

We're kind of scared that you know, like something will happen to her hey. So that's one of the challenges is to make sure that she's okay and you know. (Riel)

I don't know, it's scary when it's like storming out. Yeah, she still has to go, yeah, and that's the scary part. (Tricia)

It impacted, yeah, it impacted me because I'm close with my family, and I love my family and I don't know what I would do if I lost her. (McKayla)

Chapter Summary

This chapter provided a general description of the sample with the “who, what, and where” of events encompassing the experiences of Misipawistik Cree Nation caregivers of a family member requiring RRT in The Pas, Manitoba. The major theme of resilience and the subthemes were presented.

Chapter 6: Discussion and Reflections

Indigenous patients who relocate to urban centres for RRT experience a poor quality of life and increased mortality (Anderson et al., 2012; Kolewaski et al., 2010). To gain a comprehensive sense of the issues which touch Indigenous patients with CKD, the implications of this condition must also incorporate caregivers in their community (Komenda et al., 2015; Davison, 2016). This research generated a description of First Nations caregivers for a family member living with ESRD, using the words and experiences of First Nations families in a remote region of Manitoba. In this chapter, the findings will be discussed within the context of the literature. The study's strengths and limitations will be presented. Based upon the study's findings, recommendations will be made for future practice, administration, and research.

In this study, all of the participants co-constructed living with a family member requiring RRT as a purposeful life of adversity and relations, addressed with resilience, skills and capacities in reflection of Miyopimaatisiun or Cree health and wellbeing. Each participant described efforts to access health services as complicated visits necessitating individual, family and community support. This finding supported previous research by Komenda et al. (2016) who indicated that access to health services by community members is important to maintaining health. This same understanding was repeatedly captured through the participants' narratives and expressions of deep attachment to the family member requiring RRT.

Caregiving involved relations with Indigenous and non-Indigenous agencies in a process of bolstering knowledge and capacity which was perceived as necessary to sustain the wellbeing of the family member requiring RRT. Participants were determined to ensure the health and wellbeing of their family member with ESRD and were confident that Miyopimaatisiun or "being alive well" was the best way to live a good life. It is a perspective based upon Indigenous ideologies and practices judged critical for resiliency in a locality that is predisposed to severe or

shifting environments. In frank terms, the Cree way of life is rooted to the people and the land (Adelson, 2009).

Cree way of life. The Cree way of life is considered the way that the Cree have learned to live life on the land. Adelson (2009) observed that the Cree have a notable appreciation and respect for the land which has been cultivated across several generations. In the northern Manitoba landscape, which can be harsh or difficult, Cree people have been able to prosper and build communities. Essentially, the Cree have established behaviours of living in harmony together on the land (Johnson, 2015). This proficiency merits distinction as experts push for approaches that would increase understanding and thus improve the wellbeing of Indigenous populations.

In practical applications, the Cree way of life stimulates ideas and holistic views which allow a person to view mental, physical, emotional and spiritual qualities in relation to each other (Habjan et al., 2012). Its holistic approach provides an empathetic perspective when meeting with negativity or opposition and fashions an optimistic mindset, corresponding to a raised outlook or sense of hope. This may be the reason that several participants relayed feelings of optimism during the interviews, which was unanticipated. In contrast, previous studies supported a more severe or desolate outlook in people living with CKD (Anderson et al., 2012, Barnieh et al., 2014). The connection to home and family may propel a raised or increased sense of optimism reported. This will be discussed further below.

Relations with Indigenous agencies. Participants employed a holistic ideology as they interacted with Indigenous agencies. If the relations with Indigenous agencies could be depicted, the inner circle would contain immediate family members, which is encased by a wider circle of friends and close contacts, and bordered with an outer circle of community resources. It was

indicated that concerns or issues regarding the family member requiring RRT were relayed from the inner circle to the outer circle.

It was customary to consult family and community resources; nonetheless, there were participants that claimed sufficient resources at the inner circle, due to a strong supportive family network to manage critical circumstances. On the other hand, there were individuals and families in the community who suffered a breakdown in this process due to colonialism and did not have access to sufficient resources to help cope during times of crisis. This incapacity is exhibited in the article by Hart and Lavallee (2015) which confirmed that poor health outcomes for First Nations communities have been directly linked to colonization in Canada.

The majority of day-to-day care was provided by informal caregivers that tended to oversee housing, food, transportation and mental health or social support for the family member requiring RRT. Additionally, this capability of the inner circle was comprised of relations with Indigenous individuals or families which were reliable, trusted, and often, historical relationships that extended connections to other communities (Datta, 2015). Participants were able to access these relations when they were in the region and readily used the connections to check on or assist the family member requiring RRT during treatment days. This accentuated a reliance on extended family in adjacent communities as integral to their framework of care.

Understandably, the participants were very emotional in expressing the importance of the family member requiring RRT and could not fathom life without them. Hence, a large amount of energy was devoted to keeping the family member in the community in keeping with Habjan et al.'s findings (2012). In the participants' descriptions, the family member requiring RRT was portrayed as a person bearing a wealth of knowledge and experience that was crucial to the family and community. "In addition to family responsibilities, dialysis requirements may cut across or conflict with patients' family, community and/or cultural responsibilities" imparted

Anderson, Cunningham, Devitt, Preece and Cass (2012). In the First Nation community, some families have lived in proximity to one another for many years and harboured strong ties to each other. These historical relationships were deemed to have as much intensity as family bonds and entailed a capacity for participants to rely on these supports for the care of the family member requiring RRT, should it come to be necessary.

Indigenous communities have persevered and instituted countless interactions on terms which attest to the strength of relations for Indigenous people (Kovach, 2009). In this study of First Nations families, trusted relationships were selected by participants for advice on the care of the family member requiring RRT and were more consulted than a health care provider. These associations with extended family members and close friends, constructed through kinship and past experiences, were afforded respectful designations such as an uncle or cousin. This factor is critical when educating First Nations communities about CKD. Health information would be better received with cooperative approaches that align with Indigenous principles (Steinhauer & Lamouche, 2015). The inclusion of all relevant individuals who assist in the care of First Nations with ESRD is vital to the improved education and preventative measures of the disease in Indigenous communities.

Relations with non-Indigenous agencies. Participants encountered barriers in the administration of health services. Hart and Lavallee (2015) have clarified that policies and procedures, frequently defined by federal and provincial governments, are developed by their operatives who enter communities or settlements in a hastened pace (p. 150). In terms of health care, the participants found the provision of services complex. The local health authority in the community directed these services which were generally in the form of meals and transportation; however, this administration lacked the ability to adjust guidelines to appropriately meet all the needs of patients such as an overnight accommodation, a chaperone or a sitter to mind the

children (Adam, 2015, Hart & Lavallee, 2015). Federal laws and health care policies had constraints and funded provisions that specified the minimum of care for Indigenous populations with medical conditions (Palmer, 2011). Under this governance, concerns about safety and infrastructure for the vehicle and operators, compounded by the risk of inclement conditions, and periodically strained expeditions were voiced by participants.

The participants' concerns over the health care system contrasted with the access to RRT where they freely entered the dialysis unit to see their family member. Participants reported a preponderance of good relations within the dialysis unit staff, including moments of friction for the family member requiring RRT that were addressed and resolved. The participants surmised that staff in the dialysis unit cared about the family member requiring RRT and comprehended the problems that were experienced in attending treatment. The health care providers lived in the same ecological conditions as the participants with a family member requiring RRT, and employed attitudes that afforded better understanding and relations. Within the very basis of nursing, the knowledge systems of local people and communities are needed (Bourque Bearskin et al., 2016), as well as essential in the delivery of nursing services to Indigenous communities.

Several participants reported an apprehension for the dialysis unit and a reluctance to attend treatment with the family member requiring RRT. Medicalized environments are difficult to navigate and lack culturally relevant or safe care for Indigenous people experiencing chronic health conditions (Habjan et al., 2012; Rix, Barclay, & Wilson, 2014; Smith, 2015). At the health care facility, participants were disturbed by the environment teeming with mysterious smells, sounds and equipment. Since the waiting room was in the main hallway of the building close to the elevators, there was a high exposure to the routine traffic of medical wards for individuals that were attending to family members during RRT.

Rix, Moran, Kapeen, and Wilson (2016) found a disconnection between the cultural values of Aboriginal patients with CKD and clinicians. In this study, clinicians lacked sensitivity and understanding into the history or antecedents experienced by Aboriginal People and perpetuated their lack of trust towards health services. Accordingly, Rix et al. (2016) emphasized that institutions must commit to providing resources for the building of relationships that are founded based on understanding and respect. With this desire to build relationships, clinicians can help patients and their families to select treatment choices and optimize outcomes which, moreover, increase the prospects of a richer quality of life (Barnieh et al., 2014; Cowan, 2016; Davison, 2016; Reilly et al., 2016; Winterbottom, Bekker, Conner, & Mooney, 2012).

According to Davison (2016), patients with CKD require a better understanding of illness trajectories and want to hear about the impacts of treatment to quality of life, including physical and cognitive function, and the alternatives that enhance survival. The ability to dialogue over colonial impacts could uproot the causes of worse patient and graft survival in Indigenous kidney transplant patients. As added benefit, this commission aligns to the principles of patient oriented care for health care providers.

First Nations communities are comprised of complex interdependent connections of Indigenous families and suitable restorative action has to distinguish the entire community as the group adopting treatment (Linklater, 2014, p. 92). Linklater (2014) stated that “empowerment can be achieved when the detrimental power structures in communities become flattened and the natural healers and community workers are able to bring forward ideas for growth, healing and sustainability” (p. 91).

In Manitoba, a new system of increased support was implemented which exercised care maps for tracking patient progress and optimally coordinating the renal health care team (Manitoba Renal Program [MRP], 2016). Precedent to this, the Manitoba Renal Program (2013)

participated in a screening project with several First Nations communities to detect kidney disease at the early stages, improve health outcomes and avoid the need for advanced care. These resonate with the recommendations to health care by Kelly et al. (2016) which inferred that improved Aboriginal renal patient care requires the contributions of key stakeholders like patients, families and health care providers.

Colonizing bodies. In a focus on health and healing, Kelm (1998) proposed that Aboriginal ill health was created by the colonial policies and practices of the Canadian Government, and the culturally constructed superiority of EuroCanadian medicine. Additionally, Kelm demonstrated that Aboriginal medicine was a primary practice in many remote communities throughout British Columbia, and where native healers remained to deliver an important role. Across this era, colonizing bodies emerged from the interstitial spaces of the body politic, molded by patterns of subsistence, education, beliefs and healing (Kelm, 1998).

The cultivated impacts of colonization are pervasive and have a tradition of emphasizing the dysfunctional and unhealthy elements of Aboriginal communities such as suicide and violence (Alfred, 2009). It is correct that poor health is attributable to faceless pathogens, but Kelm (1998) also determined that policy makers, civil servants, and legislators were willing to sacrifice Aboriginal beings for “provincial development”. In the experiences of Smith (2015), the implementation of health policy presented challenges to First Nations patients and families that needed health services and support for CKD, kidney donation and transplantation. Attending to the petitions of health services for kidney treatment and transplantation on behalf of the family member requiring renal replacement therapy was a significant undertaking for the participants who experienced uncertainty, atypical dictates, insensitivity, and disapproval from purveyors of the health care system.

Substantial disparities in health outcomes of First Nations people supports that the cycle of colonizing bodies has saturated the health system of Canada. With this research, participants described the incidence of diabetes in their family which led to CKD and linked the symptoms to deteriorating infrastructure and resources in the community. “We know that these populations under threat suffer from a disproportionate burden of kidney failure and other complications of type 2 diabetes and that this risk seems to be increasing over time” (Lavallee et al., 2015). The declining wellbeing of Indigenous populations signifies that colonial practices and structures are long overdue for redress and removal from the fabric of Canadian health legislation.

The contrast between relations with Indigenous and non-Indigenous agencies was readily apparent in the First Nations participants and appeals to remedy the conditions of family members requiring renal replacement therapy came from everyone affected. Policymakers must establish an intention which will help shape the future of Indigenous peoples in ways that are independent of the will of the Canadian Government (Kelm, 1998, p.177-8). At this time of reconciliation, First Nations, Inuit and Métis are requesting an equally visible representation of active and engaged responses to the processes of decolonization (Truth and Reconciliation Commission [TRC], 2015).

Knowledge and wellbeing. Participants displayed an array of knowledge about CKD and provided examples of their education and capabilities. Most of the participants were skilled and had attained secondary levels of education or years of experience in their occupation. The depictions from the participants illustrated that knowledge of health and wellbeing was gained from health care engagements and traditional activities. Furthermore, the dexterity of participants to work with Western and Indigenous agencies was influential to the care of the family member requiring RRT.

Participants rated their knowledge about CKD as adequate and related doubts over the vascular access site, diet, activity, and stability of the family member requiring RRT. Patients of CKD and their caregivers experienced detrimental impacts from the demands of renal health care treatment (Anderson et al., 2012; Barnieh et al., 2014; Cass et al., 2002; Goetzinger et al., 2012). To address concerns, the participants would look to the broader circles of relationships and supplemented their knowledge of CKD in this way. There were relationships with people considered experts such as persons that used to live with former patients, persons who were well educated or persons who had family with the same circumstance as well as the elders who held the historical knowledge of the community (Paterson, Sock, LeBlanc, & Brewer, 2010).

To minimize fears or worries about CKD, participants accessed relationships which also had the potential to foster misinformation or practices that would be of little benefit to the wellbeing of the family member requiring RRT. However, as the information was from a trusted source, the participants were likely to take the advice compared with the limitations of seeking information on CKD through the health care system. Davison and Jhangri (2014) found that First Nations individuals in Canada used family and friends as a common source of health information. Upon reflection, participants were unable to recall any formal education about CKD other than individuals who chaperoned every appointment through diagnosis and learned along with the family member requiring RRT.

For patients living with CKD, communication is critical during the initiation of RRT and kidney transplant (Cowan, 2016), when the risk of graft failure could lead to a loss of viability. In the participant's descriptions, respective chaperones commonly relayed the events of a medical appointment with the family member requiring RRT to the inner circle of immediate family. If this person misinterpreted the statements of the health care provider, then the misinterpretation trickled to others who cared for the family member requiring RRT. In research

on communication, Cass et al. (2002) noted that “a shared understanding of key concepts was rarely achieved” from interactions between Aboriginal patients with ESRD and their health care providers. The daunting environment of the hospital and the confusion experienced by Aboriginal people over renal care remains well known (Rix et al, 2014)

The family must have clear information to assist with the intricacies of CKD. Across provincial and regional levels of health care, there are increasing efforts to address CKD (Chartier et al., 2015), which uniformly coexist with impediments in health service entitlements to First Nations individuals, families and communities that lobby for health care services (Haworth-Brockman, Bent, & Havelock, 2009). Participants attending to the health care interests of a family member requiring RRT verified that health policies and procedures were restrictive and unresponsive to their needs. Therefore, enhancing relationships between First Nations families and health care providers is required for the optimal care of First Nations with CKD (Lavalley et al., 2015). Indigenous families and communities have unique aspects such as food insecurity and infrastructures which enlarge the prevalence of health issues in Canada (Skinner, Hanning, Desjardins, & Tsuji, 2013). Policymakers appear to be indifferent to the living conditions of Indigenous people (Adam, 2015; Hart & Lavalley, 2015), which eventually impact the health care needs of CKD patients. As rectification, First Nations in Canada are calling for assurance to exchange information about wellbeing with confidence that it will be sensitive to the distinct health needs of people and communities (TRC, 2015).

Relations are a fundamental aspect to the thinking of Cree people and emblematic of their Indigenous worldview (Johnson, 2015). Within Indigenous knowledge systems, Kovach (2009) as well as Rix, Barclay and Wilson (2014) portrayed important tenets like respect, reciprocity, relations and protocol. Cree ideology has been called or referred to as Nêhiyâw, which literally means “I am Cree,” with leanings to holistic thinking (Kovach, 2009). This knowledge system is

an exceptional part of First Nation practices, with the most sacred forms of wisdom sensed in dreams, fasts, sweats, vision quests and ceremonies (Fergusen & Philipenko, 2016; Kovach, 2009). The wellbeing of Cree people hinges on an ability to overcome obstacles threatening their survival through environmental, social, political, or physiological factors (Adelson, 2000). The health and wellbeing of northern communities is tied to life on the land, which Adelson (2000) maintained, "...can only be fully understood within the context of the connections between land, health and identity."

The guide to building connections with First Nations individuals, families and communities is through honouring Indigenous ways of thinking (Datta, 2015). Conscientious measures to health care must concede the importance of place and culture to the people, as well as the value in ceremonial, camping, and hunting pursuits which are innate to the Cree way of living (Adelson, 2000). It is imperative to remove the symptoms that defeat understanding, especially the disgraceful conduct of clinicians recounted by participants, where there was discord mounting to negative, traumatic scenes. These moments showcased the flaws in the health care system which was experienced by First Nations individuals and families accessing the system for the treatment of ESRD (Habjan et al., 2012; Rix et al., 2014).

Participants recalled with clarity when they were stifled and their advice to clinicians on the care of their family member requiring RRT being cast aside without proper consideration. This marginalization occurred in the presence of the family member requiring RRT and touches on the malevolence and ignorance that participants faced in the health care system. Hart and Lavallee (2015) cautioned that, "these experiences of social exclusion and its foundations in individually, structurally, and socially based racism, are a critical root to variations in the incidence of and death from various diseases" (p. 152). In several instances, participants weighed cumulative historical or experiential knowledge and showed reluctance to involve health

information resources for additional support. This indicated that gaining reinforcement of health information from renal agencies was lax or ineffective and clarified the basis under which participants with a family member requiring RRT were apt to report their knowledge of CKD as adequate.

Still, some participants displayed higher or raised knowledge surrounding CKD and improving health conditions which included diet and symptom management for the family member requiring RRT. Since a major portion of the community was pressured with providing food, shelter and water, the descriptions indicated that participants overcame regular hurdles to keep the family healthy, happy, and stable as well as avert their own possible prognosis of CKD. In similar respects, Banerjee et al. (2017) found that the implications of food insecurity for clinical practice, research and public health are derived from the association of low income adults with CKD who were more likely to develop ESRD owing to the direct effects of diet quality on kidney health.

In this study, there was continual anxiety that the family member requiring RRT would be lost from the community, as a progression of ESRD, and relocated for treatment at distant, major health care locations. This was compounded by a fear of reliving the experience, because the cycle of CKD has crossed generations in Indigenous communities (Anderson et al., 2012; Rix et al., 2016). Several participants requested renal health facilities and services which guarantee that the family member requiring RRT would remain part of the community. Participants were deeply dismayed to witness the effect of treatment on the family member requiring RRT and believed this would disappear with more relevant local care. Indigenous patients who received appropriate CKD care and education were more satisfied with their care and benefitted from being closer to family support (Barrett et al., 2015; Smyth, Hartig, Hayes, & Manickam, 2015).

Capacity and wellbeing. To ensure the family member requiring RRT was Miyopimaatisiun or “being alive well”, participants focused on providing food, warmth and physical activity. Food and shelter were singular priorities described by all the participants with a few going so far as to demonstrate this capacity. It was discernible that the infrastructure of the community was beleaguered with overcrowding, food insecurity and limited access to clean running water. Participants described concerns over maintaining diet, keeping the house and family clean, seeking disability-appropriate housing, and dealing with roadways that continually impeded access in their bid to support the family member requiring RRT. Often living in poverty, First Nations adults and children are meeting food insecurity, intergenerational trauma, poor housing, stress, emotional distress, and low educational attainment (Lavallee et al., 2015).

The poor health status of Aboriginal people has become a systemic problem as the population increases and transfer payments from the Canadian government remain based on older census information (Haworth-Brockman et al., 2009). Under present health care contribution agreements, health care services in First Nations communities will fall behind the health care needs of the growing community. This is happening in an environment with escalating costs in the cultivation of traditional food for First Nations families (Skinner et al., 2013); a strategic resource in maintaining the diet of persons with CKD. Participants were able to find moose, ducks, geese and fish for the family member requiring RRT but still reported a desire to supplement these staples. Regions with proven food insecurity are also areas where issues of chronic health are increasing (Banerjee et al., 2017), qualified by conditions where settling for fast food is much cheaper and readily available to individuals who have been assigned few alternatives.

People with clinical knowledge of CKD that were generally consulted for renal health support by the participants consisted of the nursing station staff and a doctor that attended the

community on a weekly basis. Experts in renal care such as a dialysis nurse or a nephrologist were located at the nearest renal health care unit in The Pas, which is more than 200 kilometers away. Haworth-Brockman, Bent, and Havelock (2009) observed that “given the geography of Saskatchewan and Manitoba, community isolation and the vast distances that must be traveled, transportation for medical purposes is a prime issue for all Aboriginal women” (p. 20). In health emergencies, the family member requiring RRT was rushed out of the community and participants who had questions about care turned to the wider circle of friends and relationships for reassurance.

As a means to reduce stress, participants would anticipate cultural events that improved the quality of life and outlook of their family member requiring RRT. Cultural events helped to fulfil community togetherness and the participants found this was missing in the life of the family member requiring RRT since initiating and traveling to therapy. The participants saw that the community offered these gatherings to transfer teachings and this interaction was being subverted in a hasty and surreptitious manner, by the demands of CKD treatment. As members of the community, Indigenous ESKD patients have obligations and cultural responsibilities with the younger generation (Anderson et al., 2012), to convey the significance of place and territory, interconnectedness among members and the relationship between land and overall health and wellness (Tang, Community Wellness Program, & Jardine, 2016) At the time, the lives of participants were more focused on the daily regimen of the family member requiring RRT which meant they were hard pressed to take the family member and join in community gatherings. The participants and their families rarely took a holiday because there were too many barriers to obtaining treatment for the family member requiring RRT external to the renal replacement unit to which they were assigned. This coincides with a survey of Canadian patients, and their caregivers by Barnieh et al. (2014) that summarized concerns about the quality of life on

dialysis, an urgent need for psychosocial support, and resources to facilitate travel for patients on hemodialysis.

In the interviews, participants were hesitant to estimate the health status of the family member requiring RRT and, over time, this affected their optimism as the family member's life was increasingly unstable. The availability of trained professionals for the psychosocial care needs of Canadian patients and their caregivers, both in and out of the dialysis unit, could help to relieve the hardship of living with the disease (Barnieh et al., 2014). Similar trepidation surrounded the narratives about kidney transplant and living donors where participants reported sporadic consultations from health care providers. Initially, the participants were pleased that the family member requiring RRT was going to have transplantation and then, all of a sudden, the procedure was halted which left them repeatedly deflated. During the preparations for kidney transplantation surgery, the participants were separated from the family member and missed crucial health information which left them unclear on the aborted surgery. Research into caregivers which accompany transplant candidates related that caregivers' health needs and psychological wellbeing were overlooked, prior to and during the transplant process, because the patient is the primary focus of attention by health care providers (Goetzinger et al., 2012).

After termination of the transplant, the stymied participants felt the health care system was insensitive to the family member requiring RRT which grew to speculation that their campaign for kidney donation was being sabotaged. First Nations participants have maintained that the current system of health care provides no recourse to direct complaints or concerns over the treatment of family members. The impression left by the transplant attempts was that the participants could not improve or expedite the situation. This finding was similar to Habjan, Prince and Kelley (2012). "Our research further demonstrates alienation from and mistrust by

the First Nations communities toward the governing bodies,” issued Habjan et al. (2012), “as well as pervasive feelings of misunderstanding and disempowerment” (p. 220).

For First Nations with CKD, renal health care support should be provided in communities to assist families with routine aspects as well as overriding challenges (Komenda et al., 2016; Reilly et al., 2016). Indigenous communities seek amenities dedicated to tackling chronic disease conditions in which to advocate their hidden issues, share in knowledge and build up relations (Kelly et al., 2016; Rix et al, 2016). It was disheartening to see the role of attending to a family member requiring RRT straining First Nations family capacities while caregivers reported that they were only offered the minimum of consideration and respite.

Caregivers are an unseen, unpaid population and the backbone of health care. Over one-quarter of Canadians have provided some type of care to a family member or friend and have become increasingly important to maintaining the health and wellbeing of those living with chronic health conditions, disabilities or aging needs (Statistics Canada, 2013). The workforce is a resource that is critical to the care of the vulnerable and unwell in Canada. Greater caregiver loads and psychological stress have been linked to poorer perceived quality of life and self-related health in caregivers of patients with end-stage renal disease (Goetzinger et al., 2012). “Having too many tasks and responsibilities when caring for a family member or friend can be a major source of stress,” explained Turcotte (2013), “especially when caregivers feel they lack the resources to meet the needs of their care receiver” (p. 5). In the depictions of the participants, the caregiver role required several people within the immediate family. In addition, caring for the family member requiring RRT entailed a designated individual to coordinate the completeness of care which is represented by the Blue Bear and emphasizes the centrality of culture in this relationship.

The Blue Bear. It was a deliberate part of this research process to perform ceremony such as smudging and prayer using sacred medicines and an eagle feather, as well as participating in sweats, and honouring the seasons. This also necessitated showing respect for the research process which engendered behaviours from the researcher that were never rushed and always deliberate. These would instigate thoughtful acts and words that were created in a good space. It is intrinsic to Indigenous culture to locate spiritual aspects, and be guided through the teachings of the ancestors (Adelson, 2000; Kovach, 2009).

The Blue Bear was symbolized as demonstrating love and devotion for the family member requiring RRT. As well, the strength and the fierceness of the bear to protect and care for the family member are similar to the tenets of the Bear Clan. Clans go across cultures and nationhood as well as facilitate understanding of spiritually gifted roles, responsibilities, belonging, purpose and meaning in life (Assembly of First Nations & Health Canada, 2015). The bear has come to symbolize the strength, love and resiliency of the participants. In the vision, the Blue Bear was always emanating this buzzing blue energy. Following the vision, I became aware that a blue bear is included in the logo for Jordan's principle, ensuring universality in the provision of services to First Nations children in Canada (FNCFCSS, 2018).

Holding to the principles of Indigenous health and wellbeing, Miyopimaatisiun in the family member requiring RRT was the overall goal of the Blue Bear. The experience of the Blue Bear was an amalgam of relations with indigenous and non-indigenous agencies met in the course of attaining ample knowledge and capacity to ensure Miyopimaatisiun. It is an experience that demonstrates resiliency in extreme or trying conditions among Indigenous groups and individuals (Grandbois & Sanders, 2012). In discussions with Indigenous elders from Northern Manitoba, Hansen and Antsanen (2016) found that traditional teachings, culture, community, first languages, spirituality, and identity were factors which assisted in promoting

resiliency. The general appraisal of the participants was that they would manage to overcome somehow and readily cite of the generations who have lived in the community. The capacity to maintain a balance or resiliency in this challenging environment is symbolic of the bear including the sense of optimism which was observed in the participants.

There has been a definite enthusiasm to portray leaps of insight in research but the moments or visions that are part of the research or within it have been notably absent from scientific record. Rather, spiritual aspects were enacted throughout this endeavor which included giving of tobacco, acknowledging the land, expressing gratitude, requesting guidance from the ancestors and accepting moments that were inexplicable. Marquina-Márquez, Virchez and Ruiz-Callado (2016) construed that in qualitative research, “efforts to revitalize identity linked to spirituality means thinking about the person as fundamentally connected to the environment and spiritual forces that provides guidance and healing” (p. 36). In the end, the holistic approach of this research produced the overall finding of the study in which the love, fierce protectiveness, strength, and constant devotion of the participants were well depicted by the bear.

Current efforts to address renal health care in Canada are devised on regimented treatments with a high cost which utilizes a disproportionate amount of health care resources (Lavallee et al., 2015). First Nations individuals, families and communities look to relationships which are basic to their way of thinking and working (Kovach, 2009). To strengthen and fortify Indigenous people, it is time to look to the communities that are directly affected by health disparities and build the relations which support community frameworks and health care initiatives (Bardill & Garrison, 2016; Boksa, Joobar, & Kirmayer, 2015; Habjan et al., 2012; TRC, 2015). This action must also recognize the uniqueness of Indigenous groups and quit the propensity to centralize or streamline services; as such processes are not sensitive to the history, needs and perspectives of the community (Kotalik & Martin, 2016; Steinhauer & Lamouche,

2015). Indigenous people must be afforded the means to address and decrease the incidence of CKD in the population using their worldview as the avenue to issues which have bearing to the population (Anderson et al., 2012; Bardill & Garrison, 2016; Komenda et al, 2016; Lavallee et al., 2015; Reilly et al., 2016; Rix et al., 2016).

The findings of this study support the extensive research on the enablers and barriers of CKD management programs to Indigenous people (Anderson et al., 2012; Lavallee et al., 2015; Reilly et al, 2016; Rix et al, 2015). It is clear that CKD is one aspect in the lives of individuals who ascribe to a future full of hopes and aspirations (Schick Makaroff et al., 2013). With access to renal health care support and services in the community, First Nations individuals could improve the care of the family member requiring RRT and incorporate traditional practices which would enhance their overall quality of life and reduce mortality. Accordingly, health care ought to welcome alternatives and suggestions from families and patients that allow them to be part of the treatment including the consideration of other health alternatives such as traditional medicines and remedies. In this prospect, be prepared to abandon dated concepts like noncompliance because the purpose of Indigenous life is to keep going, to strive, to look ahead, to move forward, to learn from what has taken place in the past, to Miyopimaatisiun, and to always live the Cree way.

Limitations

The experiences of the eight participants may not be transferable to off-reserve First Nations caregivers of family members requiring RRT or to on-reserve caregivers when on-site dialysis units are available. The distance to the treatment unit for the family member requiring RRT was an aspect unique to the experience of participants in this study and does not cover those experiencing access to proximate hemodialysis facilities.

It must also be acknowledged that the unique ways of knowing of the Cree participants, while indicative of a dominant Indigenous culture to the region, cannot be assumed to be correspondent with all First Nations, Inuit and Métis groups. The semi-structured interview may have deterred the participants from discussing their experiences in the manner that they may have wanted or precluded the opportunity to share their entire stories.

Despite these limitations, this study contributed to the evidence by: a) establishing the experience of Misipawistik Cree Nation caregivers, b) demonstrating the distinct needs of First Nations individuals, families and communities facing the epidemic of CKD, and c) supporting previous research about barriers to improving the wellbeing of Indigenous patients with CKD and their caregivers in Northern Manitoba. Based on the study findings, recommendations will be made for future health practice, administration and research.

Recommendations

It is recommended that the following aspects are considered for future health practice, administration and research in CKD management and prevention. In terms of health practice, the findings point to the need for more culturally relevant educational tools. For the restoration of its most marginalized and disadvantaged citizens, culturally fluent care must be anticipated from within the fundamental core of health practices in Canada.

The administration of health policy and procedures under the current process should be reviewed. In Canada, the prevention of CKD is more cost effective (Ferguson et al., 2017) than what is being met by the province, region and country with the costs of hemodialysis treatment and the reduced uptake of cheaper alternatives in First Nations with ESRD. Deliberate strategies to tackle the social determinants of health, such as food insecurity, poverty, unemployment, and substandard housing, is warranted for this same population that is seeing an increased incidence of the complications of diabetes (Martin, Yurkovich, & Anderson, 2016).

Further study is required to document the experiences of First Nation individuals and families seeking health services and education for CKD (Paterson et al., 2010). Using decolonizing methodologies, it is prudent to investigate the mechanisms that promote resiliency in these communities. This entails considering the ramifications of kidney disease through a holistic lens that illustrates the relationship between kidney function and the entire body system. It must be based on the worldview and linguistic practices of First Nations communities such as Misipawistik Cree Nation where land based activities and traditional healing methods are part of life. Lastly, there is urgency for suitable interventions which remedy the misconceptions, fears and knowledge of Indigenous people about kidney donation and transplantation (Davison & Jhangri, 2014).

Chapter Summary

The purpose of this study was to explore the experience of Misipawistik Cree Nation caregivers of a family member requiring RRT in The Pas, Manitoba. This research enhanced knowledge by generating a description of First Nation caregiving for a family member with ESRD, using the words and experiences of First Nations caregivers.

Participants co-constructed living with a family member requiring RRT as a purposeful life of adversity and relations which were addressed with skills and capacities meant to reflect Miyopimaatisiun. Each participant depicted efforts to access the health services as complex.

Relations with Indigenous and non-Indigenous agencies, and securing knowledge and capacity were required to sustain the family member requiring RRT. Participants were determined to ensure the wellbeing of their family member with ESRD and confident that Miyopimaatisiun or “being alive well” was the best way to live a good life. It is a perspective instituted upon Indigenous ideologies and practices judged critical for resiliency in a locality disposed to severe or shifting environments. This resiliency was symbolized through the vision

of a Blue Bear which substantiated the incorporation of spiritual dynamics to the curative process. Limitations and recommendations of the study were offered.

Ekosi. All my relations.

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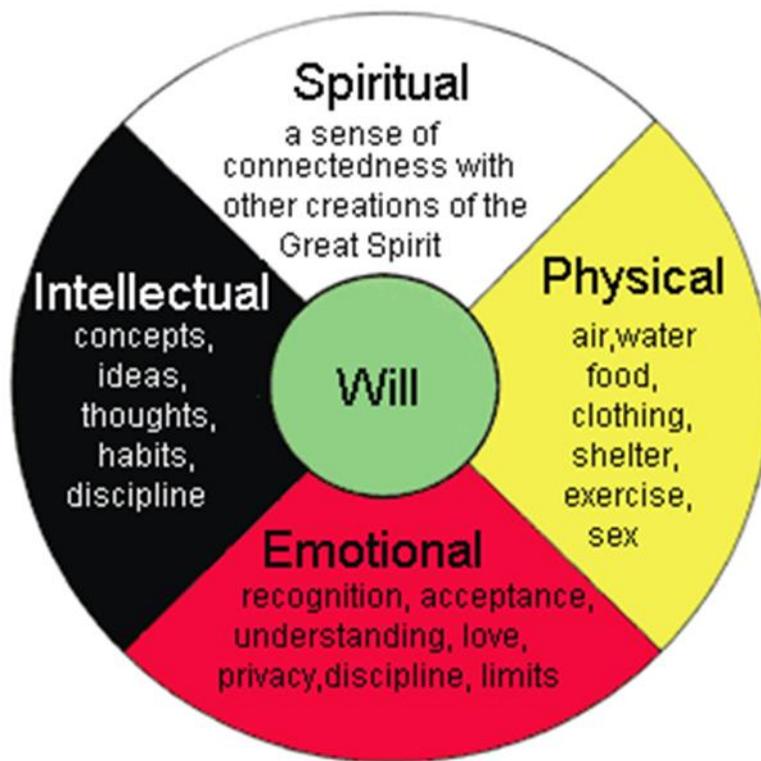
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Appendix A

Medicine Wheel



(Graham & Leeseberg Stamler, 2010, p. 10)

Appendix B

Map



Manitoba Renal Program location map

(MRP, 2014)

Appendix C

Recruitment Poster

**First Nations & Kidney Failure**

Do you have a family member who takes treatment for their kidneys?
What is it like to have a family member who uses dialysis or has a transplant?
Do you have any information or experiences that you would like to share?

I am a graduate student at the University of Manitoba. I am conducting a research study entitled, **“The experiences of First Nations families when a family member requires renal replacement therapy in The Pas, Manitoba.”** I am interested in learning about your experiences about having a family member who takes treatment for their kidneys or has a kidney transplant. This study has been approved by the Education/Nursing Ethics Review Board at the University of Manitoba and The Pas Health Centre.

Would YOU like to participate in a RESEARCH STUDY?

You can participate in this study if you:

- 1) Are of First Nations heritage,
- 2) Have a family member who has taken treatment (peritoneal dialysis, home hemodialysis, hospital hemodialysis, or transplant) for their kidneys for longer than 1 month,
- 3) Are over 18 years of age, and
- 4) Can speak and read English.

If you agree to participate, we will make arrangements to meet in a private location. I will ask questions about your experiences and audio-record our conversation. This conversation will take approximately 1 hour of your time. Your name and the name of your family member will not be used in any study documents or reports.

Upon completion of the interview, you will be provided with \$25.

If you would like more information or if you would like to participate in this study, please contact me @ [REDACTED] or umcontoc@myumanitoba.ca

Crystal Cook

Appendix D

Recruitment Script (Radio)

Megwetch and thank you to (name of radio station) for the opportunity to speak. Tansi, (title) First Nations members. I would like to tell your listeners about a study that I am conducting for my Master's Thesis at the University of Manitoba. It is entitled The Experience of First Nations Families with a Family Member on Renal Replacement Therapy in The Pas, Manitoba. I became interested in this topic because I am a First Nation woman from Misipawistik Cree Nation, and I have family members who required hemodialysis treatment. I became a dialysis nurse and now I am pursuing a Master's Degree in Nursing to learn more about family members' experiences so that I can make recommendations to support families and communities through this difficult time.

The purpose of this study is to explore how First Nations families experience living with a family member on renal replacement therapy. I am interested in learning how family members address the various functions of living with a family member on peritoneal dialysis, home hemodialysis, health centre hemodialysis or a kidney transplant and how this particular situation may influence their life. I wish to understand the matters that arise from living with family who has End Stage Renal Disease and needs treatment. This experience has not been studied in-depth yet the number of people who are First Nations and go to renal replacement therapy is growing.

If you are a First Nations adult (over 18 years of age) who has a family member that has received renal replacement therapy for longer than 1 month and you are able to understand, speak, and read English, I would like to learn about your experiences.

Participation in the study is voluntary. You can drop out of the study at any time with no negative consequences and interviews will be arranged to accommodate you. If you have a family member on peritoneal dialysis, home hemodialysis, health centre hemodialysis or kidney transplant and you would like to share your experiences with me, we will meet and I will ask you questions about your experiences. Our conversation will be recorded and it will require about one hour of your time. Upon completion of a one-hour audio-recorded interview, I will provide you with \$25. The audio-recorded interview will be typed word for word and I will remove all names and the name of this community from all study documents to protect participants' identities. Names of participants and the name of the First Nation community will not be used on any study documents or reports unless it is deemed appropriate by the Chief and Council. I will read the transcripts of the interviews to determine the essence of families' experiences and then I will write a report. I hope that community members will consider participating in this study to share their thoughts and experiences. All participants and the Chief and Council will receive an executive summary of the study's findings. Please refer to the notice posted in the band office for information about my study. Ekosi.

If you would like to hear more about this study or if you are interested in participating in an interview with me, please call me, Crystal Cook, at [REDACTED] or through email to u, m, c, o, n, t, o, c, at myumanitoba.ca, that's umcontoc@myumanitoba.ca.

I will say it again... Crystal Cook, at [REDACTED] or through email to u, m, c, o, n, t, o, c, at myumanitoba.ca, that's umcontoc@myumanitoba.ca.

Appendix E

Letter to Chief and Council



UNIVERSITY
OF MANITOBA

College of Nursing

Helen Glass Centre for
Nursing
57 Curry Place
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204)474-
7452
Fax: (204) 474-7682

DATE

Research Project Title: The Experience of First Nations Families with a Family Member on Renal Replacement Therapy in Manitoba

Researcher: Crystal Cook, Graduate Student

Sponsoring Institution: Manitoba Centre for Nursing & Health Research

Advisor: Dr. Donna Martin, College of Nursing, Faculty of Health Sciences, University of Manitoba, 204-474-6716

Dear (name), (title) First Nation:

I am a graduate student at the University of Manitoba in the College of Nursing, Faculty of Health Sciences. I am conducting a qualitative study on the experience of First Nations families when a family member requires renal replacement therapy.

I am writing to you at this time to request permission to invite adult members of your community to participate in my research study titled: The Experience of First Nations Families with a Family Member on Renal Replacement Therapy. I plan to interview adult members of the community, who have family members with End Stage Renal Disease that require peritoneal dialysis, home hemodialysis, health centre hemodialysis or a kidney transplant, about their experiences.

Eligible participants will be First Nations adults who have a family member utilizing renal replacement therapy and are able to understand, speak and read English. Recruitment of participants will require posting the attached notice in public domains in your community. If any adult community members are interested in participating in this study, the notice informs them to contact me directly. Their participation will be completely voluntary. I will obtain written consent from all interested participants before performing the audio-recorded interviews. Please note that their participation will involve being interviewed for approximately one hour to share stories and/or experiences relating to having a family member on renal replacement therapy. The interviews will be arranged with each participant for a mutually convenient time and private location suitable to each participant. Upon completion of the interview, I will provide the

participant with \$25. Participants can withdraw from this study at any time with no untoward consequences.

Upon completion of the study, I will share an executive summary of the study's findings with all participants and you. I would like to meet with you to discuss the findings and co-develop recommendations.

Participants' names and the name of the First Nation community will not be identified in any study documents or reports. I will acquire your written permission prior to publication of the study's findings in academic journals and prior to presenting the study's findings at a conference. If you would like more information or clarification of any part of this study, as outlined above, please contact me, Crystal Cook at [REDACTED] or umcontoc@myumanitoba.ca

The Education/Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project, you may contact the Human Ethics Secretariat at 204-474-7122, or Margaret.bowman@umanitoba.ca

Thank you for your consideration of this request.

Sincerely,
Crystal Cook
Graduate Student

Appendix F

Informed Consent Form



UNIVERSITY
OF MANITOBA

College of Nursing

Helen Glass Centre for
Nursing
57 Curry Place
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204)474-
7452
Fax: (204) 474-7682

Project title: The Experiences of First Nations Families with a Family Member on Renal Replacement Therapy in Manitoba

Principal Investigator: Crystal Cook, BN. Graduate Student, College of Nursing, Faculty of Health Sciences, University of Manitoba

[REDACTED], umcontoc@myumanitoba.ca

Research Supervisor: Dr. Donna Martin, Assistant Professor, College of Nursing, Faculty of Health Sciences, University of Manitoba
(204) 474-6716, Donna.Martin@umanitoba.ca

Thesis Committee Members: Dr. Elaine Mordoch, Associate Professor, College of Nursing and Dr. Paul Komenda, Associate Professor, Internal Medicine, University of Manitoba

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

You are being invited to be interviewed by the principal investigator regarding your experiences as a First Nations adult with a family member on renal replacement therapy. This research is being conducted as a thesis research project in the requirements for completion of a Masters in Nursing, University of Manitoba. The primary goal of the project is to better understand the experiences of First Nations families when a family member has End Stage Renal Disease and requires peritoneal dialysis, home hemodialysis, health centre hemodialysis, or a kidney transplant. Interviews will be held in any location that provides reasonable privacy and is agreeable to both of us. The interview is not expected to exceed one hour in length.

You will be asked a series of questions about your experiences of living with a family member on renal replacement therapy. The aim of the project is to understand First Nation family members' experiences of having a family member on renal replacement therapy. You will be

invited to share your stories and experiences of living with a family member who requires renal replacement therapy. Throughout the interview, you will be invited to provide information that you believe to be important to better understand your experiences as a First Nation individual with a family member on peritoneal dialysis, home hemodialysis, health centre hemodialysis or who may have a kidney transplant.

With your consent, the interview will be audio recorded using a small digital recording device. The digital recording will be typed word for word and the principal investigator will remove your name and any identifying features from the transcript of the interview. The transcript will be read and reread by Crystal Cook and Dr. Donna Martin to identify common and unique features that describe First Nation families' experiences of having a family member on renal replacement therapy. Your name and the name of your family member will not be used in any study documents or reports. The name of your home community may be used in study documents or reports if permission is granted by the Chief and Council.

You will be provided with \$25 cash at the completion of the interview.

Please note that sharing one's story carries with it the risk of experiencing emotional distress. With this possibility in mind, a list of counseling resources in your area has been attached to this consent form for your assistance. In the event that you experience emotional distress during the interview, the audio-recording device will be turned off and you will be asked if you would like to take a break or if you would like to continue. There may be some direct benefits to you in terms of having the opportunity to describe to a concerned listener experiences that you may have found challenging or rewarding. More long-term, you will be contributing to a more informed understanding of the experiences of First Nations families in Manitoba with family members on renal replacement therapy.

With your permission, in approximately two to four weeks following the interview, I will contact you to share a copy of the typed words from your interview. I will send you this document by email or by Canada Post. I will ask you to read the document and indicate if it is accurate or if you would like me to make revisions to what you told me. This contact will be optional and I will ask separately for your consent to do so.

At the end of the project, which will be in 02/16, you will have the option of receiving a brief summary of the study's findings.

At the end of the project, I will be presenting my findings to Band members in your community. In addition, I will publish the study's findings in academic journals and will present them at professional conferences. However, in all cases, I will do so without revealing identifying characteristics such as your name and the name of your family member. Nonetheless, given the relatively small size of the population in the northwest region of Manitoba and their familiarity with each other, there is a risk that some elements of your story may be identifiable to others. I will only use direct quotations from the interviews after removing identifying details, so they cannot be attributed to any single person.

The only persons who will have access to information collected in the project are Dr. Donna Martin, my research supervisor, and I. All information will be kept strictly confidential. The

digital audio-recordings of the interviews will be transferred onto a password protected computer file. When the transcript has been completed, the digital audio-recording on the recording device will be deleted. Digital recordings, and all electronic documents related to the interviews will be stored on a password-protected computer file on the University of Manitoba shared S:drive (only accessible to Crystal Cook and Dr. Donna Martin). Hard copies of the signed informed consents will be stored in a locked cabinet at the University of Manitoba.

I will transcribe the digital recordings of the interviews word for word and, in the process, remove your name, the name of your family member, and all personal identifiers. Hard copies of the signed informed consents, interview transcripts, and reflective journals will be destroyed in 06/20 using the University of Manitoba's procedure for destruction of confidential material. All electronic files will be deleted in 06/20.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the researcher from her legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

The University of Manitoba Education/Nursing Research Ethics Review Board has approved this research. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

If you agree to each of the following, please place a check mark in the corresponding box. If you do not agree, leave the box blank:

I have read or had read to me the details of this consent form.

My questions have been addressed.

I, _____ (print name), agree to participate in this study.

I agree to be contacted by Email or Canada Post to review transcript.

Do you wish to receive a summary of the findings? Yes No

How do you wish to receive the summary? E-mail Surface mail

Mailing Address: _____

Email Address: _____

Participant's Name: (please print) _____

Participant's Signature _____ Date _____

Researcher's Signature _____ Date _____

Appendix G

Short Demographic Survey

PLEASE NOTE: DO NOT PUT YOUR NAME ON THIS PAPER

You may choose not to answer any or all of these questions with no negative consequences. I am gathering this information to provide a general description of the study participants. For example, I may report that most of the study participants were women.

Age _____ Male Female Marital Status _____

Occupation _____ Full-time Part-time Casual/Seasonal

Band Assistance Yes No

Student Yes No Program _____

Education level _____

Number of people who live with you _____ Number of bedrooms _____

Relation to family member who uses renal replacement therapy _____

Renal replacement therapy type: Peritoneal Dialysis Home Hemodialysis
 Health Centre Hemodialysis Transplant

Family member who uses renal replacement therapy lives with you Yes No

Distance to the nursing station or health centre _____

Distance to the health centre with a hemodialysis unit _____

Do you go with your family member to renal replacement therapy? Yes No

Are you the primary caregiver for the family Yes No

How would you rate your understanding of End Stage Renal Disease?

Excellent Adequate Poor

Appendix H

Semi-Structured Interview Guide

I am going to ask you some questions about your life and living with a family member on renal replacement therapy. The knowledge that is provided by the expertise of community members, such as you, will be invaluable to this research. This depiction is not available or captured in text. Your identity will be kept confidential and you may choose to decline to answer at any time. The responses that are given will be analyzed and condensed into a report to assist in the care of these patients.

1. How long have you lived in (title) First Nations and what is your position or role in the community?
2. What is your connection to the person who requires treatment for their kidneys?
3. What is your understanding of end-stage renal disease?
4. What is your understanding of the [type of renal replacement therapy identified on demographic survey]?
5. Please tell me how you were informed that (family member) would require treatment for their kidneys. What is it like to have a family member that needs renal replacement therapy such as (identified treatment)? How does this influence or impact your life and other family members' lives?
6. What challenges have you experienced living with a family member on renal replacement therapy? What supports or services have been helpful to you and your family?
7. What do you think is needed for people who live in your community that have a family member that goes to or needs treatment for their kidneys? What resources or services would help you and your family?
8. Do you have any other stories about your experiences having a family member on renal replacement therapy?
9. Is there anything else that you would like to tell me?
10. Is there someone else in the community who would be able to share their experiences of having a family member that uses renal replacement therapy? Would you mind contacting that person to tell them about this study? Please ask them to email or phone me if they are interested.

Appendix I

3 Stages of Qualitative Data Analysis

Data Reduction

- Process of selecting, focusing, simplifying, abstracting and transforming the data
- Process is ongoing as data is collected
- Initially, data is organized into clusters through grouping related or similar data
- Coding schemes are developed through the progressive marking, sorting, resorting, defining and redefining of the collected data
- Coding of the data is accomplished through the basic steps of sampling, identifying themes, building codebooks and marking texts

Data Display

- Organized, compressed assembly of information that assists in drawing conclusions
- Can be in the form of graphs, flow charts, matrices or any other visual representation that helps us understand what is happening
- Select quotations to illustrate themes and provide readers with the opportunity to understand and validate those themes

Conclusion Drawing and Verification

- Begins at the beginning of data collection but is not finalized until the project is completed
- Description of the relationship between the themes
- Conclusions are drawn to describe, make contributions and contribute to better understanding
- Validation of emergent themes and subthemes is sought through various means such as rechecking of the text, verification by colleagues, participant consultation or application of the model to a new case
- Constant comparative analysis by the researcher ensures that the analysis reflects the participants' beliefs rather than their own

(Lobiondo-Wood et al., 2009)