Weaving the Sweetgrass and Porcupine Quill Birch Box into a Methodology:

The Living Stories of Chronic Kidney Disease for First Nations People

by

Mary Smith
B.Sc. N., McMaster University, 2002
MScN, York University, 2011

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Requirements for the Degree of

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Supervisory Committee:

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ABSTRACT

The thunderstorm encroaches, the smoky raven like clouds float over my spirit. This writing takes place at a time of mourning, a deep and lonesome sadness for family relations who have passed over the last few years, many having died of kidney disease. Yet, I cannot escape this feeling that has filled the silent spaces and the deeper meanings that lie behind spoken words. These are the words of my relations, the words that fill these empty pages, the words of an enduring past and present. As I begin, I wonder, how will I shape these passages into an articulation that may bring an illumination of all that has happened over the last few months since the inception and then ethics approval of this work. So here I shall offer an understanding of the background that brought this study forward. I will recount the progression of thought that precipitated the methodology. Like water that flows and is fluid, this writing has become realized to be ever changing, boundless and repelling conventionality. It is not just a story about living with kidney disease, this is a passage that motions and travels through history making interconnections amidst the broader social, political and contextually traditional and creative ways of being. Through the methodology of the sweetgrass porcupine quill box, living stories came forth within the context of a First Nations community. Sharing circles involving ten participants conveyed the living stories of kidney disease that illumined the significance of Indigenous Knowledge, relationality, cultural safety and equitable access.

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I would like to express the tremendous gratitude and thankfulness that I have for my supervisory committee at the University of Victoria. Dr. Carol McDonald, my supervisor, is truly one of the kindest and wisest persons I have ever met and her ongoing support has been instrumental in making this dissertation possible. Dr. Jacquie Green and Dr. Anne Bruce also provided immense support throughout the past few years since our initial meetings. Without the vast knowledge, gentle guidance and open mindedness from everyone, I would not have been able to persevere through this major undertaking. For this I am forever grateful.

I need to express my gratitude to my family who stuck with me and cheered me on when I would spend frenzied hours, days and months totally absorbed in my writing and reading often feeling guilty for not always being there for everyone.

Chi-Miigwetch also to my community, the Beausoleil First Nation, for their incredible and ongoing support and to all who participated in the Kidney Circle. Everyone has always welcomed me with open arms and I always want to be able to return this incredible warmth, compassion and love back.

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Dedication

This dedication cannot forget all who have gone to the spirit world — to my dear family and community members, when I meet you in my dreams I feel so relieved to be able to hug you again and know that you are always in my heart. I miss you terribly but I *know you are always there!*

Anishinaabe Prayer

Oh! Great Spirit, whose voice I hear in the winds
And whose breath gives life to everyone,
Hear me.

I come to you as one of your children,
I am weak… I am small… I need your wisdom
and your strength.

Let me walk in beauty, and make my eyes ever
behold the red and purple sunsets.

Make my hands respect the things you have made
and make my ears sharp so that I may hear your voices.

Make me wise, so that I may understand what you
have taught my people and
The lessons you have hidden in each leaf
and each rock.

I ask for wisdom and strength,
Not to be superior to my brothers, but to be able
to fight my greatest enemy, myself.

Make me ever ready to come before you with
clean hands and straight eye.
So as life fades away as a fading sunset,
My spirit may come to you without shame.
ALL MY RELATIONS
(Author Unknown)

Nimiigwechwindam maabaa bimaadiziwin. (I am feeling grateful for this good life.)

Chapter One: Introduction

This dissertation focuses on research that addresses the living stories of chronic kidney disease (CKD) through a contextual methodology depicted through the lens of Indigenous philosophies, specifically Anishinaabe worldview that involves crafting work of the sweetgrass and porcupine quill birch box. The living stories of CKD are inextricably interwoven and interconnected with the methodology that emerges from an Indigenous way of knowing and being. In this regard, the research questions pertain to the living stories of kidney disease *and* their interpretation through the methodology. The research questions are further depicted in chapter 3 where the research process is detailed. The methodology is emphasized as being contextual and fostering the living stories of CKD. The methodology is described in chapter 2. Critical to understanding the dissertation research is a discussion of my underlying assumptions and situatedness and is the intent of the opening chapter. Central to this discussion is my family experience with CKD and kidney transplantation and my autoethnographic account of this experience. Additionally, this chapter presents the scholarly processes and publications that became the impetus for this research project about living stories of CKD and the unique methodological approach.

What led me here? What are my assumptions?

To help answer these questions I will begin with a story called Awakening. This story sets the stage and foundation for my PhD studies and my passion for the topic of kidney disease and methodology arises.

On January 25th, 2010, I awoke from the anesthesia after the removal of my left kidney. This kidney had been transplanted to my son who had suffered from seriously comprised renal function as a result of having an aggressive form of immunoglobulin A (IgA) nephropathy. Upon awakening, I remember feeling the most horrific burning pain; I yelped and screamed “THE PAIN!!!” I remember seeing the anesthesiologist fuddling frantically with the intravenous lines and injecting something into the intravenous port. Oh the relief, like the tranquil clear waves of Georgian Bay sweeping over me, soothing and numbing, I succumbed to deep sleep, oblivious temporarily to the chaotic hospital commotion around me. Morphine as I discovered would be a double-edged sword, freeing from the knife like pain but only to undergo the horrendous side effect of nausea later on. In this nauseated state, the hospital environment seemed unbearable and obnoxiously tumultuous. I yearned to go home, back to the peaceful sparkling pristine sandy and rocky shores, back to my community to be immersed within the friendly laughing and sometimes gossipy chatter and to hear the elders’ softly spoken Ojibwe language. Strange in a way, as nurse myself for many years, having also worked within similar hospital settings, caring for similar surgical situations I was now living on the flip side, I remember thinking, I am now the patient. My son too, in the intensive care unit, was also the patient and such a young one. To me, he never looked like he fit this role, my son at the age of twenty-five was very tall with beautiful features of his Ojibwe Mishomis (grandfather in Ojibwe). Back at my hospital bedside, the nurses were struggling with my morphine pump, intravenous lines and dangling catheter so that they

> could put me in a wheelchair so I could visit my son in the intensive care unit. Finally, there in the intensive care I saw my precious beautiful child in this incredibly high tech environment reserved for transplant recipients. He was no longer a greyish pale colour but a lovely pink amidst what seemed like a thousand intravenous lines, tubes, wires and monitors. Smiling, he thanked me "Chi-meegwetch (meaning big thank you in Ojibwe), you saved my life mom!" This was a miracle and I wept feeling the immense gratitude for the hospital and everyone one who made this possible. He still had in his hand the semaa (tobacco in Ojibwe) pouch he held during the surgery. This semaa is representative of the powerful spirits and by gifting and receiving semaa, this cultural teaching is about 'giving thanks to them (spirits)' for their support that carried us through. I was so grateful to the hospital for fully supporting this practice that allowed the semaa to be held in his hand through one of the most fear-provoking situations my son had ever experienced. It had been such a long battle, years of worry, endless medical appointments and tests. The success of the kidney transplant meant the world to me, a life for my child to just be able to do what we all do and take for granted. (Smith, 2016a)

Why, I would come to wonder, why is this not happening more often in my community? So many of my relatives have CKD and many had died while on dialysis. I am one of three people in my community who donated one of their kidneys to a family member and the only one I know who had been involved in a preemptive transplant. Preemptive transplants happen before dialysis is required and are supported through research as sustaining the life of the organ or decreasing time to kidney rejection (Huang and Samaniego, 2012). However, Kelly and Minty in 2007 explain “body-wholeness and spirit-transfer values might be issues for aboriginal patients contemplating organ donation” (p. 1463). Conversely, I had never heard or felt this way in my community about organ donation. On the contrary, I felt supported by my cultural perspective and community to go ahead with this life saving donation. At a deep gut level, I knew I was doing the right thing and I was developing a strong heart felt yearning to speak loudly about my experiences that might further and possibly make some difference to improve health care and health education for Indigenous peoples around the world (Smith, 2016a).

The preceding narration was originally written for my substantive candidacy paper in 2016 and I have included it here as it unleashes the story of a life-changing event that informs my doctoral research. This personal story also begins to unfold my underpinning assumptions. I am aware of the power of storytelling within the ways of the people who are my family and community. In this regard, it is also my assumption that Indigenous[1] ways of knowing and being are conveyed through sacred stories and storytelling, including ceremonies and creations that are unique to place and people and their spoken language. For instance, my contextual orientation derives from what is otherwise known as the Ojibwe speaking people of Ontario, Canada. It is the ways of the people of this particular geographic area, their language, ceremonies, traditions and craft making that shape and influence my thoughts and this writing. The living story lives on through the people, throughout time and interconnects with the land, ceremonies, and traditional ways of living like hunting, fishing and artful crafting. As such, Ojibwe knowledges will be described at length beginning in chapter two, the crafting work of the

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[1] The term Indigenous is used interchangeably with the terms First Nations and Anishnaabe throughout the dissertation.

sweetgrass porcupine quill box has inspired the methodology that envelops and guides this effort. Lopez and Willis (2004) clarify that decisions about which methodology to use stem from the researcher's assumptions and values. Fleshing out one's assumptions is integral to the process and these assumptions must be made transparent to the reader. In this regard, I feel that as a researcher I cannot place myself separate from the research I am immersed in. I see my personal history and cultural upbringing reflecting upon the interpretation and the ultimate outcomes of the research. In this way, I am drawn to research methodologies that uphold the personal story and is woven with cultural and western ideologies.

From this depiction, I begin in the first chapter with an exploration of significant passages of several of my writings as well as conference presentations associated with autoethnography and pedagogy. The autoethnographical and pedagogical papers are considered as informing and leading to the study that begins in chapter two. In this manner, this dissertation builds upon what I have learned through the earlier phases of my PhD work. In chapter one, the discourse revolves around the published and unpublished writings in association with conference presentations. All of this work expresses the significance of the kidney health experience perceived through an Indigenous contextual lens. Chapter one also delves into my positioning and relationship with the community that is significant to the dissertation research. In chapter two the sweetgrass porcupine quill birch box methodology is introduced and delineated. This includes the literature review. Chapter three delves into the specifics of the research and was originally developed as part of the dissertation proposal presented to the supervisory committee in 2016 and has been expanded upon in relation to the research. Chapter four elucidates the living stories. Chapter five concludes with the discussion and implications for health care and nursing.

1.1: Anishinaabe-izhitwaawin

Since starting the PhD Nursing Program in 2013 at the University of Victoria I have embarked upon an extraordinary introspective journey. A compelling heartfelt yearning to help my family and community through their kidney health experiences has always fueled this excursion. At the same time, the longing to make things better also revived a way of knowing and being to be of great significance for my family and community, as well as the nursing and health care profession I partake in. This quest has allowed me to come to know my family, community and myself better and through this knowing, to discover our resilience, strengths and challenges.

It is from this premise where history, culture, traditions, language and knowledge within the Anishinaabe contextual realm emerge as the center of my PhD journey. Language takes a pivotal place. Basil Johnston, an Ojibwe scholar, storyteller and language teacher, explains:

> In my tribal language, all words have three levels of meaning: There is the surface meaning that everyone instantly understands. Beneath this meaning is a more fundamental meaning derived from the prefixes and their combination terms. Underlying both is the philosophical meaning. (Johnston, 2013, p.6)

The word “Anishinaubae” or Anishinaabe means a person with worthy intention (Johnston, 2013, p.6.). Johnston goes on to describe the story of Nanabush who represents the Anishinaabe. Nanabush meant good things for the people and is central to the mythical sacred stories. Through this story of Nanabush the Anishinaabe identified themselves similarly with pride through their well-meaning intentions (Johnston, 2013). On this goodhearted path, the Anishinaabe word kik-inoowaezhiwaewin means "to guide, point the way; laws, principles, policy(ies)" (Johnston, 2011, p.28). This links with the Anishinaabe word, izhitwaawin, reflecting certain ways of beliefs (Ojibwe People's Dictionary, 2015). Taken together the word, Anishinaabe-izhitwaawin reflects meanings of the people with good intention, similar to the account of Nanabush all of who are guided by their knowledge, beliefs, values, traditions and ceremonies. Anishinaabe-izhitwaawin then becomes the guiding force and the heart of this passage that has fueled all the activities and has led to 'my coming to know' the research methodology and dissertation (See Figure 1). Anishinaabe-izhitwaawin also holds within its meaning the concept of Mino Bimaadiziwin that speaks to achieving balance through living in a good way (Day, Silva & Monroe, 2014). "When we live according to our original instructions as the Creator intended, we are in balance and acknowledge where we come from, our Creation Story" (Day, Silva & Monroe, 2014 p. 37). The ensuing section unfolds the personal story known as autoethnography and is weaved with storying from an Anishinaabe philosophy.

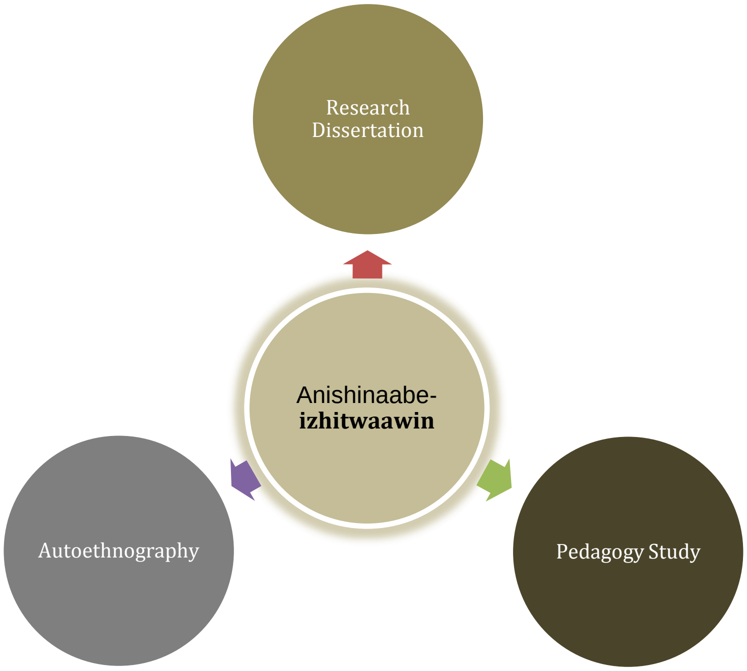


Figure 1: PhD Journey

1.2 The Relevance of the Autoethnographical Story.

"What is life? It is the flash of a firefly in the night. It is the breath of a buffalo in the wintertime. It is the little shadow which runs across the grass and loses itself in the sunset" (Chief Crowfoot in Morritt, 2011). Here, Chief Crowfoot in his final words offers a perspective that cuts to the core. In my personal and family experiences of kidney disease I have often faced death and bereavement and was left with a feeling of struggling to come to terms with such losses. Wrestling with life experiences, I am always reminded of the stories from our ancestors and those who have passed before us. The stories that surface from our lives, our illnesses and even our final days offer deep insights, a way to find meaning in death and illness as life processes in themselves. In my yearnings to extend such powerful life stories often fraught with sensitive experiences, I became interested in autoethnographical research. As a form of research, autoethnography tells the personal story of what is life within unique contexts and circumstances. Autoethnography seeks to make a relationship with the listener and has therapeutic potential (Ellis, Adams & Bochner, 2006). In my view, autoethnography meshes intricately with storytelling approaches and the need for authenticity that is fundamental to Indigenous research.

> The Indigenous researcher - burdened with the challenge to perform academically rigorous research and the desire to practice this research respectfully - is often overwhelmed with internal conflict. Indigenous autoethnography represents one methodological option to such researchers. Indigenous autoethnography seeks to establish itself as a legitimate and respectful means of acquiring and formulating knowledge, by combining the tradition of storytelling, with the practice of academic research. (Houston, 2007, p.45)

It becomes apparent that autoethnography has struggled to be accepted amongst the cannons of research methodologies where it can be a challenge to seek ethics approval and publish (Wall, 2008; Ellis, Adams & Bochner, 2006; Smith, 2015a). Yet, autoethnographies are increasingly being circulated for their significance in describing perceptions of disabilities, chronic illnesses and gender diversities that heighten awareness and sensitivity (Merryfeather & Bruce, 2016; Richards, 2008; Schneider, 2005).

In 2013, I was able to provide a presentation at the Canadian Indigenous Nurses Association (formerly the Aboriginal Nurses Association of Canada) conference in Vancouver, British Columbia. The presentation, *The Gift of Healing in a First Nation Community: Learning from the lived experience of Kidney Donation*, became the precipitous event that would eventually develop into an autoethnographical study.

During this presentation, I retold the ancient legend story of the makisin waabigwann or moccasin slipper.

> The story as I know it is about a young Ojibway maiden who had a brother who she loved very much. He could move quick and agile crossing the ice in the winter and could swim like a fish. He had the role of travelling to other villages to deliver messages for his community. Sadly, one day in the winter cold the whole village got sick including the girl's brother. Because he was so ill, he could not travel to the medicine woman who lived across the water that was now thin ice. The young girl decided one night to cross the thin ice to get the medicine that would save her brother and the village. Like her brother, she was able to lightly cross the ice and on the other side the medicine woman gave her the medicine pouch with healing herbs. The girl was anxious to bring the medicine home to heal her people so she left in the dark night to cross the frozen lake. A blizzard had come and the snow had formed deep drifts. She heard the ice cracking but she whirled through the drifts like her brother had taught her. Coming to the other side, her moccasins had been lost in the deep snow. Her feet were now bleeding and frost bitten but she persevered and then collapsed at her village. Her people came to the rescue and bandaged her feet. The medicine saved her people and her brother. In the spring, the girl and her brother looked for her moccasin by the lake. Instead where she had bled were now beautiful flowers shaped as a moccasin. Do not pick a moccasin flower, if it is picked it will die. It grows there to mark the courage and strength of the girl who saved her people from the terrible disease (Author Unknown).

Figure 2 - Makisin Waabigwann

This ageless story originated from the people who lived in the area around the great lakes of Turtle Island. The illness the girl faced in her community reminded me of the suffering associated with kidney disease that I observe far too often in both my family and community. I could also relate to the challenges she faced in crossing the ice to her community in the winter to bring the healing medicines. For my family and community members crossing the ice to receive dialysis care or related medical care is a common experience. Like walking on ice or "inaudigaukoowin" (to walk on ice in Ojibwe) as in the story of the makisin waabigwann, there have been challenging experiences in trying to improve health care for those with kidney disease in my community through Indigenous ways of knowing and being (Johnston, 2011, p. 102). Through an autoethnographical voice, it was possible for me to describe my positioning as a researcher and moreover as a mother with a child, family and community struggling with CKD and End Stage Renal Disease (ESRD). The story of the makisin waabigwann is similar to my autoethnographical story and demonstrates how legendary stories can make meaningful connections to personal circumstances. The stories can bring strength, hope and wisdom through times of hardship. From this presentation, I began to realize how my personal story might hold great meaning for those listening. The personal story may speak to the heart of those who face similar fears and triumphs; it may bring learning and understanding otherwise not known.

My personal story came to light in 2015, in the article "Nagweyaab Geebawug: A retrospective autoethnography of the lived experience of kidney donation" (Smith, 2015b). This work was also presented at the Canadian Association of Nephrology Nurses and Technologists conference in 2015. The presentation was entitled *An Autoethnography of Kidney Donation within a First Nations Context.* The autoethnographical narrative delineated the author's personal perspective of kidney donation within the family relational context of a First Nation community. In the autoethnographical sense, I emphasized the "I" as depicting who I am in relationship to the community, an insider and within a First Nation community with many relations. Within varying research paradigms, there is an importance for the researcher as being relational with the community and being essential to enabling trust within communities. This research experience became the starting point in the progression of research activities to build upon relational research as a person within a family and community struggling with Chronic Kidney Disease (CKD). The Indigenous ways of being and knowing that I am familiar with, in the context of my life shines through this autoethnographical story of my personal experiences of kidney donation to my son (Smith, 2015a). The experience of writing the autoethnographic study led to a journey beyond conventional research methodologies. Having been largely educated in a medical model that positions evidence based hierarchy and prioritizes quantifiable evidence, I initially felt almost doomed to failure in my initial steps towards the development of an autoethnography. Despite this, I also realized first hand through my cultural footing within an Anishinaabe community and family how story and revelations of one's own perspective into their life journey has incredible power and meaning that could fuel the heart and help towards healing. Autoethnography as a research methodology fostered the story and Indigenous Knowledge. It also positions the researcher as the participant, an insider thereby fostering understanding of the researcher's positioning as genuinely connected within the community. Using autoethnography I was able to express my heartfelt position within kidney research.

From this standpoint, I prepared an article for the journal, *Cultural and Pedagogical Inquiry* in 2015, which sought to link qualitative research with the First Nation sociopolitical context (Smith, 2015a). This article spoke to and articulated the importance of autoethnographical work in exposing societal injustices through stories and accounts of sensitive experiences. Autoethnography in this sense has been an ideal methodology, given my situatedness inside a cultural place of knowing and being. Indeed, my insider's connectedness within the cultural context may foster an insight that may be of particular interest to those pursuing 'best care practices' that are deemed to be ethical and conducive to equitable care.

In the summer of 2015, I attended the Eleventh International Congress of Qualitative Inquiry in Urbana-Champaign, Illinois. Attending this conference and preparing for my presentation helped me to write the autoethnographical paper. At this conference, I presented, *The experience of writing an autoethnography of organ donation within a First Nations context*. This was an opportunity to share the challenges of autoethnography in terms of ethics and its history of growing acceptance. Autoethnographical writing necessitates demonstrating credibility and verisimilitude by depicting exactly how the situation actually happened so that the truthfulness and authenticity of the situation described is accepted (Ellis, Adams & Bochner, 2010). The story needs to speak to the reader and their circumstances. For instance, the autoethnography of kidney donation within the First Nation context may appeal to First Nations peoples considering kidney donation or who have families and loved ones with chronic kidney disease. It may also be relevant to health care providers required to care for those with CKD (Smith, 2015b).

1.3 Insights into Methodology: Linking with Pedagogy in Nursing

In the 2014 article, "He Told Me a Dream of Animals Leaving His Heart", I attempted to assert the critical need to listen to the Anishinaabe story beyond evidence based intervention (Smith, 2014). With the publication of this article in the *American Journal of Nursing*, I began to receive a plethora of emails and invitations to discuss the need to prioritize the story, to understand cultural ways of being and knowing including the need to realize the significance of dreams. In 2014, I provided a presentation based on this article at the International Network of Indigenous Health Knowledge and Development Conference and Network Environment for Aboriginal Health Research in Winnipeg, Manitoba to a large audience from around the world. The presentation stimulated further many of the thoughts I was having about dreams and the stories within dreams that Indigenous people have traditionally sought direction and guidance from (Laughlin, 2013). A certain memory from this conference stands out in my mind. It is of an elder who spoke out to the crowd, stressing the need for the settler to come to know

First Nation language, culture and knowledge. This was prioritized as the only way to survival.

It becomes clear then, that learning about First Nation ways of being and knowing also requires learning about the traditional significance of dreams. Dream sharing was a common practice with many First Nation people. The sharing of dreams fostered social cohesiveness and strengthened relational connections essential to survival (Brody, 1981; Dei, Hall & Rosenberg, 2000; den Boer, 2012; Goulet, 1993; Lopenzina, 2015).

> Among the small communities of hunter–gatherers, dream sharing is widespread. The entities within their world (animals, plants, etc.) were regarded as sentient, responsive beings, with whom discourse could be established via dreams, visions, and trances, together with song, dance, and ritual. (Wax, 2004, p. 83)

The dreams and vision quests often involved spirits as animals that would offer assistance and communicate again in future dreams, dance and songs (Wax, 2004). In this manner, Castellano (1999) describes the type of knowledge that comes from revelations. The term ‘revealed knowledge’ refers to knowledge that comes from the spirit world through intuition, visions or dreams (Castellano, 1999). The Ojibwe word for this special spirit knowledge is Manidoo-Waaniwin (Nokomis, 2007). Memories of dreams and their meanings were highly important to the Anishinaabe. Traditional sacred stories were so revered that they occurred only orally and were not written. The living spirit of the story is embodied in the Ojibwe word, aadizookaan, who speaks through the storyteller (Nokomis, 2007; Marsden, 2014). For our people, teachings may come through dreams where connections to the physical self are maintained.

Nursing with its emphasis on holistic care may come to realize the significance of listening to the dreams of those we care for. The practice of ‘listening sincerely’ to the dreams and the stories within conveys respect and is meaningful to the therapeutic relationship (Smith, 2014). Knowing the special place of dreams within Anishinaabe culture, I struggled to discover methodologies that would consider and convey the significance of dreams as understood within many Indigenous philosophies. In addition, I also knew that my own nursing education had very little knowledge about dreams or dreaming beyond learning about the stages that include rapid eye movement or non rapid eye movement. Laughlin (2013) explains “[d]reaming among people raised in the world’s modern industrial societies stands in sharp contrast to that of people living in most human societies on the planet” (p.65). Indeed, nursing education within North America may be considered aligned with a monophasic position towards dreaming. In the monophasic orientation, dreams are less essential or meaningful to culture, knowledge systems and spirituality. Monophasic differs from polyphasic cultures where dreaming shapes knowledge systems and identity (Laughlin, 2013; Ridington & Ridington, 1970).

> In contrast, much of Western intellectual reasoning has become reductionist, materialist, and individualistic, and so dreaming is studied by biomedical professionals who deal with it as a psychophysiological process (akin to breathing or digesting), with the dream itself being the product of the dreamer, regarded as a separate and isolated being. (Wax, 2004, p. 85)

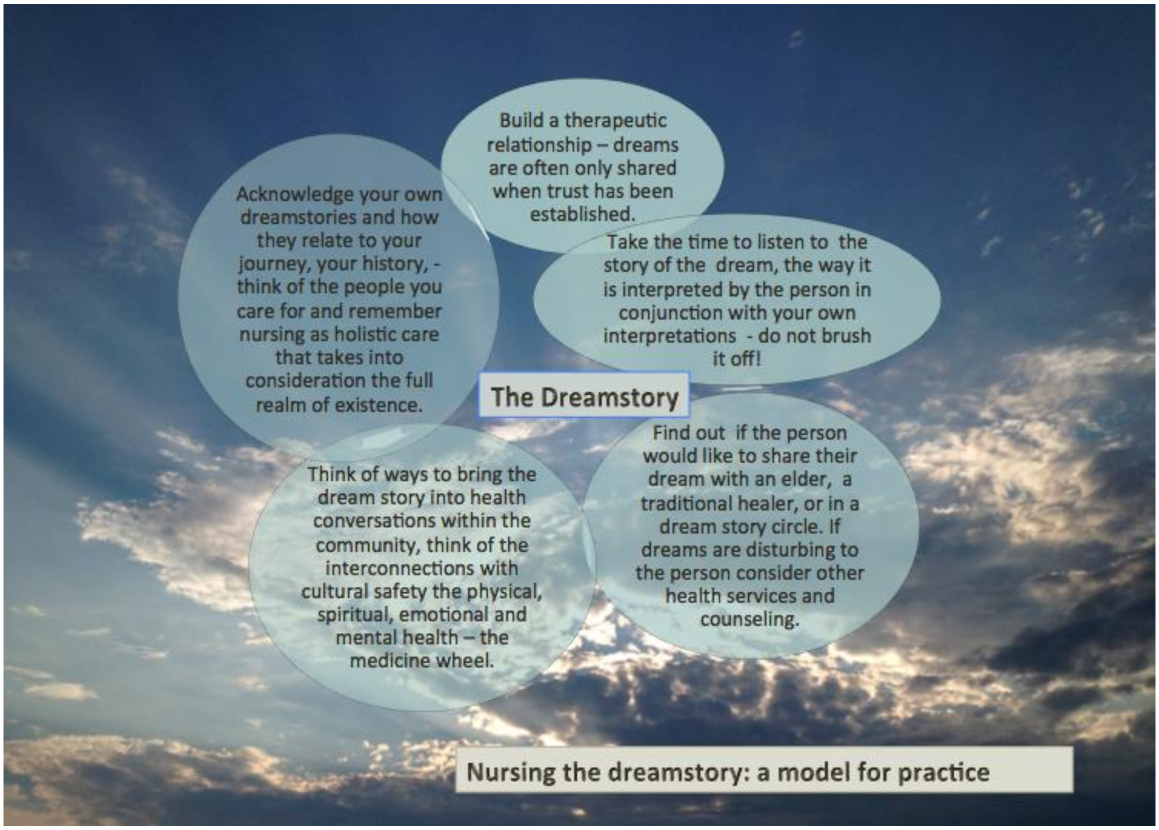
Dreams and dreaming have a special place in non-Western groups where the “distinction between waking and dream is dissolved” (Irwin, 1994, p. 20).

> However, since reality itself is an indeterminate concept influenced by imaginative and symbolic processes, there are cultures other than our own in which waking, dreaming, and various in-between experiences, though they may be distinguished, may well not be sorted out according to the simple oppositional dichotomy of real versus unreal, or reality versus fantasy. (Tedlock, 1987, p.1)

Carl Jung also saw the meaning in dreams as particularly meaningful.

> …[we] discover with astonishment that an apparently quite senseless dream is in the highest degree significant, and that in reality it speaks only of important and serious matters. This discovery compels rather more respect for the so-called superstition that dreams have a meaning, to which the rationalistic temper our age has hitherto given short shrift. (Jung, 1953, p. 24)

Understanding dreams as an Indigenous way of ‘knowing’ have yet to become familiar within nursing and nursing education. Indeed, the inattention towards the significance of Indigenous perspectives about dreams relates to the pervasive colonizing dominance. “Western modes of dream interpretation tend to closely track Western ambitions of appropriation and colonization, whereas Native interpretations are typically grounded in rituals of engagement and cooperation with the dream world and its beings” (Lopenzina, 2015, p. 5). Though there can be potential deliberation of dreams and realizing the potential importance within health care, I began to piece together a model for nurses with regards to addressing dreams. Although this is still a work in progress the following slide as presented during a conference in Winnipeg, Manitoba (year) may contribute to nursing care.



Build a therapeutic relationship – dreams are often only shared when trust has been established.

Acknowledge your own dreamstories and how they relate to your journey, your history, - think of the people you care for and remember nursing as holistic care that takes into consideration the full realm of existence.

Take the time to listen to the story of the dream, the way it is interpreted by the person in conjunction with your own interpretations - do not brush it off!

Think of ways to bring the dream story into health conversations within the community, think of the interconnections with cultural safety the physical, spiritual, emotional and mental health – the medicine wheel.

Find out if the person would like to share their dream with an elder, a traditional healer, or in a dream story circle. If dreams are disturbing to the person consider other health services and counseling.

Figure 3 - Nursing the Dreamstory

This model called Nursing the Dreamstory: A model for practice, focuses on the therapeutic relationship, inquires about dreaming with those cared for, emphasizes heartfelt and compassionate listening and being with the person in a respectful way. It prioritizes engagement with elders, traditional healers and involvement in dream story telling circles in relation with medicine wheel teachings. This dreamstory model was construed in recognition that dreaming has been essential to Indigenous peoples since the beginnings of turtle island and is intricately linked with most cultural practices fostering bonds between people. Dreams are interconnected with our life journeys are often thought of as the passageways to the spirit world. With the wisdom from the spirit world, dreams may motivate us to act or not act affording protection and guidance (den Boer, 2012; Lopenzina, 2015, Irwin, 1994).). The model as previously discussed at the conference in Manitoba and arising from the presentation was another important step towards developing the quill box methodology that is discussed throughout chapters two to five.

My intuitive and gut feelings about dreams stimulated my search for methodologies that embrace Indigenous Knowledge. Gadamerian hermeneutics is very appealing to my sense of positioning within research, in this, the researcher's preunderstandings and presence become a part of the research rather than being bracketed out. Dwelling also with Gadamerian hermeneutics was particularly interesting in addressing the meaning that emerges through language and communication. Realizing the hermeneutic emphasis on language also reinforced the critical need for Indigenous languages; of which are essential to restoration of Indigenous ways of knowing and being. I deliberated upon and sought methodology and methods genuine to the Anishinaabe ways including dreaming as "studies done in this area often rely disproportionately on Western hermeneutics to work through structures of indigenous belief" (Lopenzina, 2015, p. 4). Although the hermeneutic philosophy would become essential to another pedagogical study as discussed further on in this chapter, it was a turning point for me along my PhD journey to distinguish Indigenous methodology and to address the challenges to using Westernized methodologies for Indigenous research.

A pivotal realization came to the fore during a presentation provided with my supervisor, Dr. Carol McDonald at the 2016 International Philosophy of Nursing Conference and Philosophy in the Nurse's World Conference where I dwelled upon notions of truth, the interplay of history and colonization amidst grappling with research methodologies. An excerpt from the presentation entitled, "Exploring the potential contribution of Indigenous philosophies to nursing education" demonstrates some of my critical insights over the notions of truth prevailing in mainstream methodologies.

> The claim to being associated with truth had also led to assertions of being rightful and superior and has degraded Indigenous peoples and knowledge that are not of the dominant Western culture. The educational structures that lack critical introspection of curricula and pedagogy in terms of Indigenous Knowledge may further be an extension of the assimilative processes that have desecrated First Nations…The assault on identity resulted in extensive damage to every facet of life for the following generations and beyond. I and perhaps we struggle with the subconscious messages internalized within our own experiences as nurses and throughout our own education often devoid or blind to what really happened. Take for instance, the way Dr. Peter Bryce was treated after publishing his report The Story of a National Crime: An Appeal for Justice to the Indians of Canada back in 1922, he was basically cast out of his role within the Canadian government for attempting to bring awareness to this massive atrocity and death of children occurring in the residential schools. As nurses, nurse educators - faculty, researchers we all have an ethical responsibility to learn this untold history and engage in deep dialogue with our students and all those around us. (McDonald & Smith, 2016)

Then, in my dissertation proposal I described this situation of feeling like I was trying to fit a circle into a square. The circle represents Indigenous Knowledge that embraces the supernatural; and the square requires conformity to an objective standard that asserts itself as fact or truth where anything else is dismissed as lacking rigour, not valid and non-generalizable. The significance of the circle as one of many in an Indigenous paradigm was depicted within my candidacy paper regarding methodology.

> Indigenous relational ways of being emulate a circular pattern that resembles the Indigenous sacred circle. In ceremonies, pow wows, sharing circles, community and Chief and Council gatherings the people come together and form a circle. Understanding of one another in circle and Indigenous knowledge are shared and kept alive through this relational core within the Indigenous paradigm. The Indigenous ontology encircles oneness with the earth. "It is with the cosmos; it is with the animal with the plant, with the earth that we share this knowledge" (Wilson, 2008, p. 56). Through this circular interconnectedness, Indigenous Knowledge comprises the whole, from the living rocks, trees and people through to the universe. The sacred circle symbolizes the complete sphere where everything is connected through the relational respect and gratitude with all living things. (Smith, 2016b, p. 12)

My thinking of methods go beyond limitations of the square, as such, I sought the circle, a methodology that is true to the contextual and relational Anishinaabe ways of knowing and being.

Additionally, given my involvement as a Nurse Practitioner involved in mental health care, First Nation health and as an educator myself, I sought to further understand the potential that lies within nursing education to foster Indigenous content and learning of Indigenous Knowledge. In the article, "An analysis of Canadian psychiatric mental health nursing through the junctures of history, gender, nursing education, and quality of work life in Ontario, Manitoba, Alberta, and Saskatchewan," I explained nursing as representing a large and powerful sector of the workface that strives to optimize their collective impact upon mental health (Smith & Khanlou, 2013). This article begins to solidify the imperative for Advanced Practice Nurses and Nurse Practitioners to extend their services and full scope of practice within the capacity of mental health caregiving to First Nation Communities. Essential to this process is the necessity for a fulsome and comprehensive education concerning cultural safety and Indigenous Knowledge. In this regard, cultural safety becomes a priority as explained by the Canadian Indigenous Nurse's Association of Canada (CINA) formerly known as the Aboriginal Nurse's Association of Canada (ANAC). "Cultural safety offers further opportunities in which unequal power relations are exposed and managed. Cultural safety is action orientated and it is in alignment with the advocacy role of nurses and the nursing profession" (ANAC, 2009, p.2). Cultural safety is an imperative within professional roles, responsibilities and accountabilities held by the Canadian Nurses Association (CNA) that "[i]ncorporates knowledge of diversity, cultural safety and determinants of health in the assessment, diagnosis and therapeutic management of clients and in the evaluation of outcomes" (CNA, 2010, p. 8). Correspondingly, mental health concerns involving Indigenous peoples in Canada associates with the historical injustices through colonization and the residential school system which has resulted in intergenerational trauma (Wilk, Maltby & Cooke, 2017). Making the connections between nursing education and its power in addressing some of the root causes of mental health concerns within Indigenous populations in relation to the necessity for nurses to wholeheartedly learn Indigenous Knowledge has become an important research initiative for upcoming nursing professionals and educators.

In this realization, there is a need for respectful and central positioning for Indigenous Knowledge within nursing education. I embarked in a study with a team of researchers that sought perceptions from both the faculty and the researchers themselves from a nursing faculty regarding the learning of Indigenous Knowledge. The researchers' situatedness as being both Indigenous members of families and communities and also Advanced Practice Nurses and faculty members was presented in 2016 as a poster presentation entitled, "Exploring the experiences and preunderstandings that sparked nursing researchers' involvement for an evaluative initiative of the Indigenous content within a Primary Health Care Nurse Practitioner program" at the Indigenous Health Conference in Toronto, Ontario. From the abstract the ongoing critical analysis that occurred throughout the research was seen as "[u]nearthing root assumptions through deep dialogues amongst researchers" that "[illuminated] embedded professional worldviews that [challenged]…pervasive colonial perceptions" (Smith, Spadoni & Skioke, 2016, p.86). The researchers sought transparency with regards to their own histories as being within the relational context amidst First Nation communities and realized the significance of their personal histories and insights in relationship to faculty participants' survey and interview data.

Specifically, the evaluative research sought to explore the extent of how Nurse Practitioner education within a Canadian province encompasses CINA's core competencies. The competencies pertain to postcolonial understanding, communication, inclusivity, respect, Indigenous knowledge and mentoring and supporting Indigenous students for success (ANAC, 2009, p.5). This study culminated in the "Report on the Evaluation of the Aboriginal Content of the Ontario Primary Health Care Nurse

Practitioner Program" (Smith, Spadoni & Kioke, 2016). The researchers engaged in a hermeneutic interpretive methodology that enabled explorations to further support and enhance Indigenous Knowledge within nursing and Nurse Practitioner education. The study advocated for the CINA core competencies as a way to assess nursing education and promote further learning of Indigenous Knowledge (Smith, Spadoni & Kioke, 2017). In addition, the research has relevance with the Calls of Action made by the Truth and Reconciliation Commission of Canada in 2015.

> We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights, and anti-racism. (Truth and Reconciliation Commission of Canada: Calls to Action, 2015, p. 3)

Learning the colonial history and it impacts on health has often been absent within the nursing curricula, moreover it would be important to learn how to center Indigenous values and understand the importance of respecting Indigenous languages and Indigenous Knowledge to be prioritized within the research approach. Again this has also been set forth through the following Call to Action:

> We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and

> Elders where requested by Aboriginal patients. (Truth and Reconciliation Commission of Canada: Calls to Action, 2015, p. 3)

In this respect, this particular research endeavor was meaningful and addressed the Calls to Action and engage the Ontario Nurse Practitioner program towards meeting the recommendations as set forth. The need to consistently seek ways to further the Calls to Action requires an ongoing vigilance and learning by both faculty and students alike.

Undeniably in nursing education, the word “evidence” and “best” are enforced to further the objectivized structuring of health care that is deemed by many as being both cost effective and unbiased. Unfortunately, there continues to be a disconnect between the merits of such a health care system and the realities that prevail on a daily basis. Examples of such realities include the account of Brian Sinclair, a First Nation’s person who died in a Manitoba emergency room after waiting 34 hours for care but never received (Manitoba, 2015). Then Michelle Labrecque, an Oneida woman, who was given a prescription with a picture of a beer bottle with a slash through when seeking health care in Ontario (MCue, 2015; Alan & Smylie, 2015). In these two stories, the points being made here is that racism continues to reveal itself within health care settings and beyond. In this respect, it becomes clear that education must address racism in all courses and programs as a priority. Yet a tangible solution to practice is taking the time to listen to a person and their story. This respectful approach brings to light the underpinning experiences that must be understood in order to make decisions towards ethical and effective care. Making the time and appropriate space to do this relational work however is often not consistent with fast paced health care environments that prioritize cost efficient objective practice.

The preceding account of research initiatives, published and unpublished papers, written and verbal conference presentations have been explicated to illustrate further understanding and consideration of my core assumptions that are foundational to this study that unravels in the following chapters. In particular, depicting such assumptions in conjunction with my autoethnographical writings forms the backdrop that merges into insights regarding the methodology and links with nursing pedagogy. In this sense, the subsequent chapters build upon and draw from what has taken place during the first four years of my PhD studies. Untangling the burst of activities that have manifested into the categories of autoethnography, pedagogy and the dissertation research as centered upon Anishinaabe-izhitwaawin and distinguishing their relevance to health, nursing and education has become the colossal undertaking known as my PhD journey. This introductory chapter has also been an opportunity to begin to expand concepts and terms important to this work, including the meaning within Indigenous Knowledge, cultural safety, dreams and Ojibwe phrases. Given that this work centers Anishinaabe-izhitwaawin, the dissertation research required an Indigenous methodology that is contextual to the community. As a creative effort, the literature review, methodology, methods that are about to unfold, implore a mindset open to fresh innovative approaches.

Chapter Two: Like Water: The Quill Box and the Living Stories

As a doctoral nursing student with a focus on Indigenous health, I have often been immersed in deliberating methodologies that decolonize and emerge from an Indigenous paradigm. Resisting the objectively generalizable approaches dominating quantitative health research, I sought self-expression through autoethnographical writings of personal First Nation contextualized experiences of health care and kidney disease. With research interests regarding experiences of organ donation of First Nation peoples, I then proceeded to consider a hermeneutic study. This direction however briskly shifted following a candidacy challenge to develop an Indigenous methodology situated within my own relational experiences as a First Nation member. From this, an innovative Indigenous methodology began to emerge based upon the art form of the sweetgrass and porcupine quill birch box[2]. In this delineation, the methodology and the methods involving dreams and storytelling transpire within sharing circles as living stories further demonstrate congruence as a strength-based Indigenous methodology that is conducive to community well being and healing.

Anderson (2010) explains, the "relationship between waters within our bodies and the waters in our environments remind us of how everything is connected, and how life is dependent on these connections" (Anderson, 2010, p.13). In the same direction, the methodology signifies the relationship with the land and also the water that is interconnected with the land and everything on it. Likewise, there are deep ties to our families, communities and the stories we share together that keep our knowledge, language, spirits and hearts alive.

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[2] The sweetgrass and porcupine quill birch bark box methodology is used interchangeably with the term the quill box methodology throughout this dissertation.

Centered in the midst of ‘my storying’, is the accounts of kidney disease and my deep concerns about living experiences of kidney disease for those in my community and among other Indigenous families in Canada. For my dissertation, I wanted to extend my insights concerning kidney disease and organ donation beyond the work of my autoethnography. During this process, I struggled with mainstream methodologies, a wariness towards research where the exploitations of Indigenous peoples through research continue to resonate (Blair, 2015). Through the perspectives of many Indigenous peoples, quantitative and qualitative research may carry this stigma of distrust. “In the colonial context, research becomes an objective way of representing the dark-skinned other to the White world” (Denzin, Lincoln, Smith, 2008, p.4). Acknowledging these aspects of westernized research methods, I began to realize Indigenous methodologies as critical step in establishing trust and participation with the sole intent of improving health care conditions for Indigenous communities involved. In these deliberations, I began to realize that a methodology unique to my position within my own background is not only possible; but necessary. As a community member who has intimately lived and continues to live the experience of kidney disease, I pondered what it is in my life that delineates a meaningful path to fulfillment spiritually, emotionally, mentally and physically. Needing a deeper connection to earth, nature and dreams, I felt this was also something that was missing from the methodologies I had explored. In this predicament, I held my sweetgrass and porcupine quill birch box and inhaled the vague but lingering scent of sweetgrass. Many years ago, I recall the words of an elder that adverse feelings dissipate when smelling the sweetgrass and are replaced with good and pure thoughts. In this brief trance like state of being connected with nature I was reminded of how this box and piece of art is so meaningful to my family and community relations; and despite all the quandaries we have survived, we thrive. The beauty in our quill box, signifies the wholeness of mind; body and spirit that at one time flourished and fostered this great creativity when First Nation peoples were predominantly strong, healthy and free. This sweetgrass and porcupine quill birch bark box that I am holding within the palm of my hand, is the art form that represents our enduring cultural and relational strength, connections to the land, the language and the methodology.

In further deliberations regarding notions of the sweetgrass and porcupine quill birch bark box, I realized the transformation of a methodology that is based upon Indigenous ways of being and knowing. Potentially, drawing on aspects of porcupine quill birch bark box would also elucidate the community experiences of kidney disease in a manner that is fully respectful and benefiting to the community. Through this process I have come to view the “topic” of the living experiences of CKD by using the “methodology” of sweetgrass and porcupine quill birch bark box as tightly enmeshed with one another. In fact, I have thought of these as interconnected as water. For the purpose of this discussion and in particular the literature review, I will discuss the topic of CKD somewhat separately from Indigenous knowledges and methodologies.

In the remainder of the chapter I will present a review of the literature, using the depiction of ‘bird’s feathers’ that will represent Indigenous methodologies, CKD of Indigenous people and numerous studies that inform both the topic and the methodology of this work. The last section of this chapter addresses the philosophical foundations of

Indigenous knowledges as well as the relational axiology, methodology and methods specific to the sweetgrass and porcupine quill birch bark box.

Importance of Indigenous research approaches

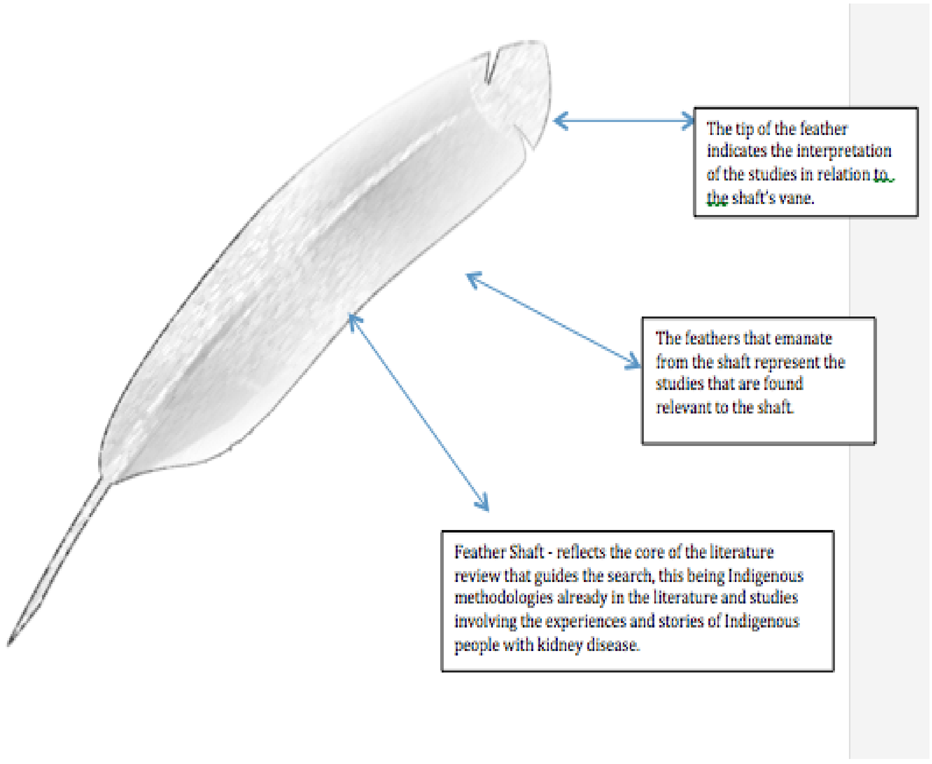
Indigenous research approaches including methods, methodologies, frameworks, models and theories that characterize Indigenous research are considered here in order to understand their applicability to the quill box methodology. As a priority, Indigenous research should embrace the histories, languages, self-determination and ways of Indigenous being and knowing (Makomenaw, 2012; Smith, 2012). The challenge to revitalize Indigenous ways of knowing and being in an effort to broaden the scope of western research is of paramount significance if the goal is to ‘benefit our communities’. The history of research within Indigenous communities was most frequently conducted using research methodologies that incorporated a non-Indigenous paradigm and focused on weaknesses versus strengths. Hence, this form of research often lacked full engagement and involvement of communities and did not centralize or prioritize Indigenous language, knowledge or historical colonizing incidents with the taking of Indigenous lands (Brown & Strega, 2005).

> In the past, Aboriginal people have not been consulted, about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters. (Royal Commission on Aboriginal Peoples, 1996, p.498)

The conduction of research in this manner often served to further undermine, belittle and oppress. “The most important elements are that research in Indigenous communities be conducted respectfully, from an Indigenous point of view and that the research has meaning that contributes to the community” (Louis, 2007, p.131). In considering the history of mainstream research approaches in First Nation communities, Indigenous methodologies hold promise of restoring and protecting traditions, ceremonies, languages, lands, sovereignty and health (Crazy Bull, 1997).

2.1 Literature Review: The Feather

Literature reviews may employ models that assist the researcher in a search strategy. Specifically, I pursued a model that was flexible, non-rigid and open to alternative ways of knowing a being. Various representations were considered to guide the literature; however, after some exhaustive contemplation I envisioned the analogy of a feather to express the intent of the studies and articles reviewed (See Figure 4). A feather is a wispy supple entity representing the flight of birds. It consists of a shaft that runs across the vane of a feather that usually comes to a point. In this analogy, the shaft signifies the purpose of the search. In addition, the shaft of the search strategy needed to also channel information from the literature that may be of significance to the life stories of Indigenous people with kidney disease. The literature search in this section of the dissertation adds further information as represented by the many smaller feathers coming out from the shaft. Feathers that stem out from the shaft denote the many studies that eventually lead to feathers conforming to the top of the feather. In my view, this is where the interpretation happens that links the quill box and the realization of what the culmination of studies are revealing about Indigenous stories of kidney disease. The feather is connected to the bird at the other end of the shaft. The bird flies free over the land and has the vision of all the valleys including hidden spots where we who are bound to the ground cannot always see. The bird's feathers signify the vast knowledge where flight depends upon all of the feathers intact. One feather or article can only provide so much information however the culmination of feathers enables flight and sight of the whole. The literature review in this analogy provides insights and glimpses towards deeper understandings that informed the quill box methodology and beyond. One purpose here involves discovering and learning about Indigenous methodologies that may illuminate or be analogous to the quill box methodology.



The tip of the feather indicates the interpretation of the studies in relation to the shaft's vane.

The feathers that emanate from the shaft represent the studies that are found relevant to the shaft.

Feather Shaft - reflects the core of the literature review that guides the search, this being Indigenous methodologies already in the literature and studies involving the experiences and stories of Indigenous people with kidney disease.

Figure 4 - Feather Representation of Literature Review

Databases used in the literature search.

This research specifically sought articles related to Indigenous research approaches using several databases including Google Scholar, Cumulative Index to Nursing and Allied Health (CINAHL), PubMed, PsycINFO, Embase, Web of Science and Cochrane Library. Search terms included Indigenous Research, Indigenous Research Methodologies and substituted the terms Aboriginal, First Nations and Anishnaabe in case where there were articles missed using only the term Indigenous. The terms were again searched including the words kidney disease, chronic kidney disease, end stage renal disease and kidney health specifying the geographic location of Canada. Backward referencing involved identifying additional articles through article references. All together over 300,000 articles including books and newspaper articles were found, however there was a paucity of articles found on Indigenous methodologies in relation to the study of kidney health, CKD or ESRD with Indigenous people in Canada. Although there appears to be a growing body of research from Australia related to research with Indigenous people that is grounded in participatory and Indigenous epistemology, there were few North American studies found in this regard. As a result, studies from the Australian context were considered to further address similar methodologies and frameworks pertaining to Indigenous populations. In addition, the inquiry also extended to books, newsletters, Internet blogs and u-tubes that garnered insight into Indigenous methodology and kidney disease.

The Feather Shaft – Indigenous Frameworks and Methodologies

There are Indigenous conceptual frameworks, models and methodologies that were helpful to the development of the quill box methodology. Distinguishing the differences between conceptual frameworks, models, theories and methodologies may lend further clarity to this discussion. Although often-overlapping meanings are associated with such terms, distinguishing their differences is necessary in the discussion of the quill box methodology in relation to existing Indigenous methodologies and frameworks. Bates (2005) describes a system of relationships, assumptions and principles as a theory. "However, for most purposes, the core meaning of theory centers around the idea of a developed understanding, an explanation, for some phenomenon" (Bates, 2005, p. 2). A methodology involves methods in relation to a philosophical theory or worldview.   The quill box methodology enmeshes the methods of the living stories from dreams and sharing circles relative to Indigenous Knowledge. "Methodology therefore explains why we're using certain methods or tools in our research" (Cram, 2013). On the other hand, conceptual frameworks suggest an arrangement of relationship and concepts whereas a model builds upon a framework and is usually tested. Models assist in the development of theories. "Indeed, there is not always a sharp dividing line between a model and a theory about the same phenomenon" (Bates, 2005, p.3). Deciphering the terms here is conducive to understanding Indigenous research where there is a range of descriptions from conceptual frameworks to methodologies. In the paragraphs that follow I discuss Indigenous methodologies of three Indigenous scholars, Lambert (2014), Smith (2012) and Lavallée (2009).

For instance, Lambert (2014) describes the Spider Web Conceptual Framework that had developed into a model. The centre is a heart, "Indigenous from a place. Your place. Your heart and voice" (Lambert, 2014, p. 220). The focus is on the diverse contextual Indigenous setting that asks "Why [do] you want to do this research" that is

"Tribal and Council Specific" and is "Your voice and passion". Around the circular web points are the imperative facets of the model including:

> …[C]ommunity interest and need, community empowerment and self-determination, community collaboration and permission, survival and recovery / moving the community past historical traumas, dissemination of data in a way the community understands, ownership and sharing of knowledge, tribal protocols / Elders / Tribal council, ethics and respect, community / Indigenous Epistemology and Ontology. (Lambert, 2014, p. 220)

The Spider Conceptual Framework at its core seeks the genuine passion where the community's best interests drive the research. To further the community's best interests the research must thoroughly understand ways of knowing and being that characterize the unique community, as well the historical colonial events that have shaped the community's present circumstances. The framework fosters respect and ethics. The Spider Conceptual Framework has meaning for the conception of the quill box methodology that also centres distinctive knowledge within the context of the community. Through the focus on traditions, ceremonies and ancestral knowledge, the methodology respects, extends and prioritizes inherent knowledge that enabled the healthful survival of ancestors. Respect for the values inherent within the Grandfather teachings (Anishinaabe teachings) are the ethical principles underpinning the quill box methodology. In turn, the methodology also decolonizes by prioritizing and embracing community traditional knowledge.

Another representation of Indigenous methodology involves notions of 'research agenda's written by Linda Tuhiwai Smith in the first edition of her book, *Decolonizing*

Methodologies, Research and Indigenous Peoples published in 1999. Utilizing the imagery of ocean tides, Smith (2012) describes four directions of north, south, west and east as the processes of healing, transformation, mobilization and decolonization respectively. At the centre is self-determination, one of the four major tides that move outwards towards the periphery of the circle. The three remaining tides are development, recovery and survival. The agenda with self-determination as central is significant to the wider goal of social justice and decolonization.

> Self-determination in a research agenda becomes something more than a political goal. It becomes a goal of social justice, which is expressed through and across a wide range of psychological, social, cultural and economic terrains. It necessarily involves the processes of transformation, of decolonization, of healing and of mobilization as peoples. (Smith, 2012, p.120)

Survival, recovery, development and self-determination as the four major tides are intricately interconnected with the four directions of healing, transformation, mobilization and decolonization. In many communities recovery often is a response to an immediate crisis that is rooted to the overwhelming history including colonized racism. Despite colonial racism, First Nation communities survive and many are in varying stages of growth and healing that is dependent on the level of self-determination. Lambert (2014) in the Spider Conceptual model, likewise, emphasizes self-determination or community empowerment. Self-determination is about control and it is through this control where languages, traditions and Indigenous knowledge come to the fore, to their rightful place as an ethical principle that is required to direct all research initiatives within Indigenous communities. This concept is applicable to the quill box methodology that requires congruence with the community's movement toward self-determination through honouring language, traditional protocols and community knowledge. The revitalization of language, ancestral knowledge and cultural customs foster traditional values that drive self-determining efforts.

The imagery, metaphors or symbols as in the Spider Web method described in Lambert's (2014) conceptual model and Smith's ocean tides enable meaningful interpretations in relation to Indigenous research. Likewise, Lavallée in the 2009 article, *Practical Application of an Indigenous Research Framework and Two Qualitative Indigenous Research methods: Sharing Circles and Anishnaabe Symbol-Based Reflection*, communicates an approach grounded in Indigenous epistemology. The article also distinguishes community-based research from Indigenous research. Although community-based research advocates active community engagement and participation in every step of the research this may actually fluctuate.

> To compound matters, the ways in which Indigenous knowledge is applied in research vary because of differences between communities in cultural traditions and teachings. Therefore, it is crucial that literature be further developed to gain a better understanding of the ways of conducting research among Indigenous communities. (Lavallée, 2009, p. 25)

Reflecting on the research with symbols, Lavallée (2009) combined symbols to form a flower where each flower represents the themes of participant stories expressed as the flower and all petals together as the collective whole story. The collective story is the culmination of the central four pedals suggesting the mental, physical, emotional and spiritual where the outer petals represent the "Stories from our past", "Native Canadian

Centre", "Martial Arts Program" and "Hopes for the Future" (Lavallée, 2009, p.36). Through sharing circles, participants reflected on symbols representative of Anishnaabe ways of knowing and being in connection with the martial arts program that supported cultural well-being. The symbols chosen by participants elicited their stories that expressed what was important and meaningful to them (Lavallée, 2009). The use of sharing circles and symbols links with the quill box methodology that is described later in this chapter. Sharing circles are means to story telling that involve meaningful symbols. The circles may bring forward stories that relate to the symbols offering deep reflections that guide towards health, relational bonding and healing.

Cairney et al. proposed the Interplay Wellbeing Framework to support policy development towards Indigenous community cultural empowerment as it is recognized that such elements are key to effective health education and employment (Cairney et al., 2017). Developed in association with the model explicated by Michael LaFlamme's 2011 report entitled, *Learning Journeys: seven steps to stronger remote communities*, the Interplay Wellbeing Framework sought to incorporate stories into a quantitative analysis. The report by Michael LaFlamme expressed how policies developed by outsiders have been ineffective in improving community circumstances. Instead an approach that seeks community members who are enthusiastic and motivated to champion specific issues are sought to be involved in the construction of policies that reflect the ways of people who should benefit (LaFlamme, 2011). From the Interplay model that connects health, empowerment, work, culture, education and community to well being, a survey was constructed. The results of surveys provided quantitative justification for holistic solutions where multiple areas need support to effect wellbeing (Cairney et al., 2017).

The study is consistent with other studies that develop frameworks and methodologies on the importance of community relationality that holds language and traditional knowledge as integral to health and wellbeing. The strong correlations reported between culture, empowerment and community indicators suggest building empowerment is closely linked to strengthening community and culture. Based on the data presented here, strengthening community means building safety, connectedness, trust and respect. Building cultural strengths means fostering connections with language, land, law and ceremony (Cairney et al., 2017, p. 10). Given the situation where government funders often seek quantitative data to determine where funding is applicable, the authors of this study devised a framework to enable the survey to collect statistical data as well as employed video documentaries of stories. In this perspective, the study is particular in providing quantitative rationalization for revitalization of Indigenous languages and cultural ways that suggest the need for supportive funding. The outcomes found strong interrelation between health, education and employment justifying the need for an overall support strategy rather than directing support to only one area. The article is of interest to the quill box methodology that centres on Indigenous knowing and ways of being. A methodology that gleams a focus on community language and traditional ways is consistent with Cairney et al., 2017's findings. The emphasis on ancestral knowledge is critical in its connection with the determinants of health including education and employment. Incorporating ancestral knowledge may be extended to further the involvement of elders in educational development and the representation of First Nations people in all societal sectors. Furthermore, the work by Cairney et al., 2017 is also in line with the self-determination angle as depicted in Lambert's Spider Web Conceptual

Framework (2014) and Smith's (2012) ocean tides model by prioritizing Indigenous language and cultural protocols in all societal sectors.

Another Feather Shaft: Indigenous People with CKD in Canada

It is well established that the situation for Indigenous people in Canada with chronic kidney disease (CKD) and end stage renal disease (ESRD) is in dire need of attention. Indigenous people not only experience higher rates of CKD (Canadian Institute of Health Information, 2017) but contend with sometime extreme roadblocks to treatment. Higher rates of infection and lengthy distances and travel to dialysis and healthcare centres for Indigenous people has also been reflected by the Canadian Institute of Health Information (CIHI, 2017).

> The study found that Indigenous patients had a 30% higher risk of being hospitalized for dialysis-related infection and a 20% higher risk of all-cause hospitalization. A 2013 CIHI study on ESKD in Indigenous populations showed that Indigenous patients were more likely than non-Indigenous patients to need dialysis and to travel longer distances to receive dialysis treatment. Indigenous patients were also less likely to receive a kidney transplant and had lower survival rates than non-Indigenous patients. (CIHI, 2017)

In a discussion of the viability of dialysis treatment to Indigenous people with CKD, Lavallee et al (2015) note "despite the high costs of providing this therapy, health outcomes and quality of life are frequently very poor, with over half of [Kidney Failure] patients dying in the first five years of treatment" (p.3). Along the continuum of kidney dialysis there is the potential of persons with ESRD to receive a kidney transplant. Kidney transplantation offers a longer life and generally an improved quality of life.

Unfortunately, despite the higher prevalence of ESRD amongst Indigenous people the rate of kidney transplantation is less. "Comparisons of Aboriginal and non-Aboriginal patients show that Aboriginal ESRD patients were less likely to receive kidney transplants … (27% versus 42%, respectively), with these differences persisting after controlling for age, sex and diabetes" (CIHR 2013, p. 7). Even worse is the fewer kidney transplants occurring amongst children in First Nation communities. "We found that the time from start of dialysis to first kidney transplant was longer among Aboriginal children than among white children" (Samuel et al. 2011, p. E671).

The studies discussed in the preceding section point to the dire need for understanding the contextual situation of CKD as well as the issues surrounding treatment and kidney transplantation for Indigenous peoples. Additional studies now discussed will be grouped together in categories of studies using Indigenous or non-Indigenous methodologies, involving Indigenous or non-Indigenous participants.

2.2 The Feathers: Studies Contributing to Understanding

The feathers are connected to the shaft of the feather and represent meaningful studies linked to the feather shaft. Indigenous and non-Indigenous studies are discussed in the sections that infuse and share further connections with the unfolding methodology in relation to CKD.

Feathers of non-Indigenous methodology

The method of using symbols to discover participant stories and perspectives in relation to a phenomenon also occurred in another study by Schick Makaroff, Shields and Molzahn in 2013. Although the study was not within the Indigenous context, symbols were found to stimulate the revelation of stories where "participants actively sought to sustain wholeness" within the context of being dependent upon dialysis (Schick Makaroff, Shields & Molzahn, 2013, p.9). Meaningful insights pertaining to health and life circumstances were conveyed through representative symbols in relation to CKD and dialysis. Stories were aroused connecting the meanings associated with the symbols in relationship to individual life priorities. Symbols and the stories they stimulate emerge as methods to discover and learn about the phenomenon of interest. In the quill box methodology, the quill box is also a symbol that inspires the living stories connecting ways of knowing and being in relation to kidney health within the broader life circumstances. The materials of the quill box symbolize traditional stories and ceremonies told in the language where meanings unfold that may give direction in life. Directions of this nature may instill hope and become a priority guiding towards inner peace and resolution.

Feathers of non-Indigenous methodology with Indigenous participants

The literature review also brought forth the PhD thesis, *Living with Renal Disease: The Native American Experience* completed by Tina DeGroot in 2016. Utilizing Moustakas' modified van Kaam's psychophenomenological method and Parse's Theory of Human Becoming, significant elements were derived from the interviews with 10 Menominee participants. The elements were classified according to the themes of "fighting for normalcy, chronic emotional and physical fatigue, living for someone else and predetermined tribal fate" (DeGroot, 2016, p.iii). In the first theme the struggle became the altered lifestyle that existed prior to having to start dialysis and the loss of control in life experienced. For the second theme, tiredness and weakness overlapped with feelings of unhappiness and helplessness. The third theme brought forth living and continuing dialysis for the sake of significant others versus the self's desire to choose the cessation of dialysis. In the final theme, the researcher gathered the data to interpret the acceptance of renal disease as fate without the need to change ways of living to avoid or deter from such a fate. The interviews for this research did not garner cultural or traditional expressions. This becomes an inconsistent approach with the quill box methodology that holds at a central place the power of Indigenous Knowledge as a decolonizing force. As described the research emanated from a methodology outside of the Indigenous ways of knowing and it is difficult to determine the effects of the non-Indigenous methodology had upon the comfort of participants in expressing a colonial history in relation to health. To synthesize further, there is also the need to address the way attunement to Indigenous ways and knowing foster strength and resilience throughout the experiences of renal disease. As the methodology utilized lacked affiliation in this study with traditions, language and ceremonies, the outcomes could not make connections of strength and resilience with Indigenous Knowledge. This is significant to the quill box methodology that expresses Anishnawbe ways of being. Alike this review, the researcher also acknowledged the dearth of literature regarding the renal health experiences from the perspective of Indigenous people. It is significant to determine research involving Indigenous people with kidney disease particularly in North America where First Nation communities vary in there geographic location and proximity to renal care and dialysis. Although DeGroot's research does not specify accessibility, the themes involving loss of control, fatigue and helplessness are of interest to consider in addition to the stresses that emerge when there exists a lack of accessibility to renal care.

Feathers of Indigenous methodology with Indigenous participants

Rix, Barclay and Wilson (2014) studied Indigenous hemodialysis recipients' experiences in rural Australia. The intent was to inform the provision of health care services as depicted by the Indigenous people themselves. Through reflective journal writing and an Indigenous advisory group the first author addressed her positioning in terms of unequal power relationships. With five Indigenous participants, stories were sought that would identify ways to improve health outcomes "through the eyes of Indigenous people" (Rix, Barclay & Wilson, 2014, p. 2). Reflexivity is rotated as priority to opposing colonial racism. The research was guided by an Indigenous worldview and community-based participatory research principles where self-determination is prioritized and the participants become co-researchers. Rigor and validity in Indigenous methodologies is captured through "relational accountability…encapsulated by principles of respect, responsibility and reciprocity" (Rix, Barclay & Wilson, 2014, p. 4). The first author's personal expression as a renal nurse, researcher and having a spouse with renal disease aligns with the tenets of relational accountability. Family is considered as the "overall mediating factor" for Indigenous people on dialysis where family fosters the enduring capacity to persevere (Rix, Barclay & Wilson, 2014, p.9). Of interest was the study's affinity with the quill box methodology that likewise seeks to ascertain the living stories based upon the values of respect, responsibility and reciprocity with the community. In addition, the emphasis on reflecting upon the relationship with participants as co-researchers and the positioning of the researcher in close proximity to the research topic of kidney disease paralleled this work. Given my own experiences as a kidney donor with First Nation family members who have kidney disease, I am aware of the connections to the participants who have similar conditions and are going through the same treatments. In this sense, the commonalities outweigh the differences between the researcher and participants and further reciprocity and relationship forming. Several research studies have been conducted in the USA using what is known as the sweetgrass method to explore topics such as intergenerational trauma and bullying prevention for Native American youth (Baez, 2011; Baez & Issac, 2013; Baez, Isaac & Baez, 2016). The sacred medicine sweetgrass as a method has been described by counselor and teacher, Mark Standing Eagle Baez (2011) who speaks to the traditional use of sweetgrass:

> In my personal experience, sweetgrass is used in spiritual cleansing. As the smoke rises, our prayers rise to the spirit world where the grandfathers and our Creator live… When I smudge myself with the ashes, negative energy, feelings, and emotions are lifted away. Sweetgrass is also used for healing one's mind, spirit, and body as well as to harmonize energies. Elders from my community describe its use as a means to cleanse our eyes and hearts so that we see and feel the truth, beauty of earth mother, and love shared through our families, friends, and communities. The ceremonies help us to grow in harmony and balance, and to feel compassion, gentleness, and thoughtfulness for others. (Baez, 2011, p. 34)

In the Sweetgrass Method as described by Mark Standing Eagle Baez and psychologist Patricia Issac, the braided strands of sweetgrass signify introspection, collaboration and continuity (Baez, 2011; Baez & Issac, 2013). The introspective strand represents the deep interconnections with Mother Earth and the Creator that bring care and wellbeing. Through this introspection and reflection with the land and the spirits balance occurs in all spiritual, mental, emotional and physical spheres. For researchers this translates into the necessity for self-reflection to avoid asserting one's assumptions or judgment to the community. The researcher needs to wait for the community to approach them, to be thoughtful and accepting of healing the spirit and to take heed of ceremonial and sacred areas. For the collaboration strand, the need to know each other is addressed; this extends to understanding the contextual circumstance including the home environment and history of intergeneration trauma. The continuity strands reflect the flexibility of the sweetgrass to bend, adapt and grow towards meaningful partnerships (Baez, Issac and Baez 2016). Sweetgrass as a sacred medicine is also highly significant to the quill box methodology. Similar to Baez's (2011) description, sweetgrass is known to my community as the hair of mother earth with healing and cleansing of negative thoughts and energy. Having sweetgrass within the research methodology signifies the ways in which ways of knowing may be congruent with self-expression, storytelling and healing.

Sinclair, Stokes, Jeffries-Stokes and Daly (2016) conducted a qualitative study involving the Western Desert Kidney Health Project that provided an outreach screening and a unique arts component for Indigenous People with CKD in Australia. Along with offering screening for diabetes and CKD the research facilitated a traditional sand-drawing art program to foster stories about the kidney health experience. The study employed Indigenous co-workers from the communities who were involved in recruitment and provided translation services for the interviews. The methods are regarded by the authors of the study as consistent with efforts to decolonize research.

This involved the art program to actively engage and understand the contexts that hold unique knowledge and traditional practices. Upon completion, the participants displayed their creations for the community. A total of 26 people in 10 communities underwent screening and interviews. The analysis of interviews culminated into four categories: “Community Leaders, Homelanders, Refuge-Seekers and the Dislocated” (Sinclair et al., 2016, p.309). Community Leaders included elders and designated community leaders who emphasized the maintenance of health through traditional ways and education. The Homelanders had strong ties to living off the land and belonging to the community. Refuge Seekers regarded their communities as being healthful and away from drugs and alcohol. The absence of being connected to the community traditional identity and lifestyle is linked to patterns of living resulting in diabetes and kidney disease. The Dislocated were those in the community with serious health issues or who needed dialysis and had to move away from their home communities to obtain such services. The majority of respondents pointed to the lack of accessibility to health care and inadequate government support as being priority issues (Sinclair et al., 2016). The study is of interest in that it employs methods that seek immersion with community traditional knowledge through an art program. The arts facilitate reflections on healthful cultural ways of being and also depict the current issues related to lack of funding to maintain health care accessibility. For the quill box methodology, this study has relevance in the approach of traditional art as a way to draw on ways of living that promote holistic health.

In 2012, Muirhead and de Leeuw provided a report entitled Art and Wellness: The Importance of Art for Aboriginal Peoples’ Health and Healing, through the National

Collaborating Centre for Aboriginal Health. Like the study by Sinclair et al., 2016, the report affirms the relationship between the arts and health. The arts extend to including ceremonies and crafting such as quill box making. “For Aboriginal peoples, strengths-based approaches must include the maintenance and revitalization of culture, something that can be achieved by encouraging artistic expressions and creative ways of knowing and being” (Muirhead & de Leeuw, 2012, p. 6). Particularly the arts and being creative can foster resilience and strength as well as contribute to the healing from the wounds endured through colonization (Muirhead & de Leeuw, 2012). Furthermore, “[u]sing art as a communication tool in a therapy setting is therefore an effective way of bridging the divide between primarily non-Indigenous health care systems and providers, and Indigenous world-views and understanding of health” (Muirhead & de Leeuw, 2012, p. 5). In this sense, this report is helpful to recognize the quill box as a form of Indigenous methodology that reflects cultural ways of being and knowing. When the quill box guides circle gatherings, stories unfold that reach deep meanings and possibilities to extend wellbeing through participation in traditional practices including art making.

Following this depiction, Lapum et al., (2014) engaged in a study where the importance of art is also at the fore. As a means to disseminate the perspective of open-heart surgery and recovery patients, data was transformed into poetry and photography exhibited as an installation. Through interviews and focus groups the installation was also evaluated. The arts in the form of poetry and photographic imagery promoted the embodied engagement with emotional responses and insights. For health care practitioners the arts installation offered a lens into what it is like to go through heart surgery, that it can be terrifying and even traumatizing. In relation to kidney disease, the study resonates in this regards, where the initiation to being dependent upon dialysis or undergoing a kidney transplant can also be frightening. Utilizing an arts approach as a means to conveying the experiences became a powerful approach to research dissemination. “If the arts are used rigorously, whereby the interpretative process is responsive to the collected data, and the presentation format is designed to enhance understanding of key findings, the arts can be a valid and meaningful form of research dissemination” (Lapum, 2014, p.12). Validity is discussed as proximal to truthfulness where the researcher rigorously questions if the artwork authenticates the stories of participants. Moreover, the dissemination should be most impactful beyond conference posters, presentations or journal articles. What would have otherwise been ignored or disregarded, the arts approach made the individual experience stand out and be heard.

Lastly in this section, Drawson, Toombs and Mushquash (2017) completed a systematic review of 64 articles to determine Indigenous research methods. Findings considered the commonality that Indigenous research fosters healing, decolonizes and addresses the equalization of power relations. In this regard, the necessity for establishing participatory engagement with the community to further a meaningful relationship that offers the community benefits is prioritized. Emanating from a resilience and strength-based focus where Indigenous spirituality, knowledge and language are prioritized emphasizes situating the research within the contextual setting and not apart from it. Storytelling as a method is consistent with relational ways of being and departs from colonizing when interpreted through the participants’ worldview. From this the contextual situatedness of the researcher, the self-determining and mutually communal and respectful involvement with community and participants and the overall emphasis on Indigenous knowledge become essential features of Indigenous research methods. Ultimately “Indigenous research methods are what they need to be for the question they are trying to answer” (Drawson, Toombs & Mushquash, 2017, p. 16). This has meaning for this work and the quill box methodology that aims to learn from the contextual living stories that are intricately connected to ways of knowing and being and to bring this learning towards meaningful action to benefit the community. Relationality extends to the researcher who is in relationship with the participants and not separated from the participants. Like the close intertwining between the strands of sweetgrass as Baez (2011) describes and the reflexivity and positioning of the researcher by Rix, Barclay and Wilson (2014), there is a fundamental heartfelt connectedness with the community.

Feathers of Indigenous participants, kidney donation and transplantation

Articles that specifically spoke to kidney donation and transplantation within Indigenous contexts are additionally pertinent to the literature review. In this regard, Wilkie-Condiff of the Turtle Mountain Band of Chippewa Indians in North Dakota focused on the experiences of organ transplantation and donation in the Ojibwe American Indians in her 2009 dissertation, *The Lived Experience of American Indians and the Organ Donation and Transplantation Process*. Her work also notes the limited research on organ donation and transplantation for American Indians. Findings included the willingness by participants to be donors despite the research that organ donation is unlikely due to cultural beliefs and to encourage others to become donors. Accessibility issues and wait times were issues for both organ recipients and donors (Condiff, 2009). Furthermore, another American study completed in 2013 by Jernigan et al. (2013)

describes changing viewpoints towards organ donation. “Most participants were supportive of organ donation and willing to donate to a family member, concurring that traditional beliefs have their place, but may not be relevant to this issue” (Jernigan et al. 2013, p.8).

Another study by Davidson, and Jhangri (2014) describes Indigenous people with regards to kidney transplantation. The research utilized a qualitative and quantitative analysis that was *not* rooted within an Indigenous paradigm. The article describes findings stating there is less willingness for organ donation in the Indigenous population of Canada. The recommendations are “[e]ducation to address knowledge deficits, emphasize the negative impact of organ failure on the community, and contextualize organ donation within the older traditional native beliefs to help First Nations people understand how organ donation may be integrated into native spirituality likely is required to increase donation rates” (Davidson & Jhangri, 2014). The study depicts the situation where westernized views emerge when non-Indigenous methodologies are implemented.

In recognizing the lower occurrences of organ donation within American Indians (AI) and Alaska Natives (AN), Jernigan et al. (2013), sought the viewpoints from AI and AN college students in the study*, Knowledge, Beliefs, and Behaviors Regarding Organ and Tissue Donation in selected Tribal College Communities*. Through focus groups involving 99 participants, the study found that many supported organ donation even with predominating views regarding body wholeness. Trust issues with health care services also emerged that may also influence organ donation messaging.

The report entitled, *Diverse Communities: Perspectives on Organ and Tissue Donation and Transplantation A Summary Report* was completed by the Canadian Council for Donation and Transplantation (CCDT) in 2005. To facilitate learning about the views regarding organ donation, sharing circles were conducted in Winnipeg, Manitoba and Saskatoon, Saskatchewan with First Nation elders and peoples involving 25 and 30 participants respectively. Sharing circle furthered the process to develop a model to engage in respectful interactions with Indigenous persons and to support and implement partnerships with First Nation groups and transplant programs. Topics that guided the groups involved awareness, perspectives and experiences surrounding organ donation in relation to cultural beliefs and values. Additionally, the groups engaged in deciphering the processes involved in deciding upon donation and ways to build relationships. Elders were consulted who gave advice on smudging, prayers and gifting. Gifting involved a small offering of tobacco and honorariums for the stories that brought balance and restoration. In this way, the circles often had a healing aspect. Circles were held for approximately 10 hours for 2 days and were audiotaped. Transcripts were themed and then re-circulated to participants for accuracy. Transcripts revealed participants speaking about dreams they had that revealed developing views about organ donation. "Then I had the dream last night about this turtle, and I realized that sometimes we give whatever we have to give, because people need it. (S.W.)" (Canadian Council for Donation and Transplantation, 2005, p. 15). Recommendations included extending the dialogue for, by and with Indigenous peoples including elders, youth, family and communities, enhancing awareness, having further Circles and specifically designed Indigenous materials (Canadian Council for Donation and Transplantation, 2005).

"There also has to be dialogue, like what my brother here talked about, they have to consult Aboriginal Elders and people in relation to health policies about Aboriginal People and to sensitize mainstream society about health, in particular in regards to Aboriginal issues in regards to healing and traditional methodologies, the way we healed ourselves in the past" (Canadian Council for Donation and Transplantation, 2005, p. 18). The report also delineates racist experiences with health care that depicts the lack of understanding of Indigenous ways of being. In addition, the need for consideration for Indigenous language interpreters for persons from remote communities who are facing dialysis and transplantation is described (Canadian Council for Donation and Transplantation, 2005).

The Feather Tip: Bird in Flight

The articles as previously discussed represent the feathers of the bird that move toward the tip informing the methodology and the ethics involved in this research project. This supports movement towards the flight of the bird that envisions the whole. To synthesize then, Smith (2012) and Lambert (2014) highlight Indigenous ontology, epistemology and self-determination as a necessity to Indigenous methodologies. Similarly Cairney et al., (2017) also emphasizes Indigenous language and knowledge in furthering the determinants of health. Lavallée (2009) and Schick Makaroff, Shields and Molzahn (2013) delineate the significance of symbols to the meaning of stories that help individuals identify meaningful life priorities, although Schick Makaroff et al is from a non-Indigenous methodology with non-Indigenous participants. Similarly, Degroot (2016) denotes a perspective emanating from a non-Indigenous methodology, even though the focus of the study was Indigenous participants with CKD. This was helpful to contrast with the studies involving Indigenous Knowledge and methodologies that come from a strength based premise.

Reflectivity is apparent in the work by Rix, Barclay and Wilson (2014). The researcher's personal proximity with the research topic of kidney disease was conducive to the study's ethics and reflectivity. Baez (2011) and Baez and Issac (2013) extend the sweetgrass method as an Indigenous way of knowing and self-discovery consistent with traditional practices and ceremonies. Correspondingly, Sinclair et al., 2016, Muirhead and de Leeuw (2012) and Lapum (2014) suggest a unique focus on art to bring forth stories as a method conducive to ways of being and knowing. Drawson, Toombs and Mushquash (2017) further solidify the aspects of Indigenous methodologies including relationality, being strength based, involving storytelling, decolonizing and focusing on Indigenous knowledge. With regards to kidney donation and transplantation Wilkie – Condiff (2009) describes the Indigenous community's positive receptiveness, while Davidson and Jhangri (2014) submit an attitude that is less accepting. Jernigan et al. (2013) further identifies views supporting organ donation and body wholeness deliberations in the context of trust issues within health care. Additionally the report from the CCDT (2005) contributes in its identification of sharing circles as a method to support rich discussions that capture perspectives mounting towards kidney donation and transplantation.

For the quill box methodology, the articles as previously considered establish essential key elements. Symbols and art forms are intricately interconnected with the stories that confer the knowledge and traditions and embrace relational ways of being. Together all the resources that have emerged from this review, along with the candidacy papers, proposal and presentations foster the all-encompassing vision that looks at not only the individual feathers (articles) but makes connections amongst all the components to transcend the fullness of knowledge. This fullness or entirety is the bird's eye view that is dependent upon the plumage of feathers that enable flight and seeing the issues or matters at hand. Similarly this view entails the critical introspection that deciphers the axiology that directs the course of the research that follows.

2.3 Philosophical Foundations of Indigenous Knowledges

An Indigenous paradigm often draws from the contextual place or the researcher's culture. As Kuokkanen (2000) shares:

> This means that cultural practices and forms of expression are reflected in the ways of conducting research: in language, style, structure, methods as well as assumptions of knowledge and the role of the researcher. Language and style, for instance, may reflect oral traditions of the particular culture, whether stories, songs, prayers or word plays. (p. 417 - 418)

An Indigenous paradigm is holistic and does not separate the spiritual or subjective from the objective (Kovach, 2010, Kuokkanen, 2000). The paradigm also "maintains a critical stand towards Western metaphysical dualism which still informs much of current patterns of thinking and research practices" (Kuokkanen, 2000, p. 417).

Hart (2010) denotes how terms like ontology may be synonymous with our perspective of reality and do not stem from the worldviews or language of the Indigenous. However, both Hart (2010) and Wilson (2008) continue to describe Indigenous paradigms in relation to ontology, epistemology, methodology and axiology. From Wilson (2008) we learn that ontology is explained as who we are, our Indigenous being. Epistemology then, denotes our thinking and knowledge about our being. Both ontology and epistemology support the methodology. The methodology in turn enables our way of thinking to learn more about our way of being (Wilson, 2008). Kovach (2010) also adds that "[t]he expectation is that a researcher will define the ontology, epistemology, and methodology according to his or her perspective and then clearly articulate that particular positioning" (p.2).

Beyond the boundaries of epistemology, Indigenous Knowledge is not something that can be simply specified or defined, "…indigenous knowledge is not a monolithic epistemological concept" (Semali & Kincheloe, 1999, p.24). To define Indigenous Knowledge may involve making comparisons where instead it is more appropriate to be open to other than mainstream realities (Hart, 2010; Battiste & Henderson, 2000). Within this comparison making is the essentialist presentation that Indigenous cultures have more or less similar forms of Indigenous Knowledge. "Not everyone who identifies with a particular indigenous culture produces knowledge the same way nor do different indigenous cultures produce the same knowledges" (Semali & Kincheloe, 1999, p.24). Depicting Indigenous knowledge as a romantic, prehistoric relic opposite to Eurocentric colonialism may have limitations to furthering the dialogue that recognizes the variability within Indigenous groups and intersections between all peoples (Semali & Kincheloe, 1999)."Some indigenous educators and philosophers put it succinctly: we want to use Indigenous knowledge to counter Western science's destruction of the earth" (Semali & Kincheloe, 1999, p.16). Taking this further, we may see Indigenous Knowledge as enabling an ontology, epistemology, methodology and axiology that is central to social justice where social justice unites with the well being of the land. The researcher's positioning within a unique Indigenous culture requires the methodology to suit the people who are intended to participate and benefit from the research. Methodology then requires congruence with the ontological, epistemological and axiological uniqueness of Indigenous peoples within the distinctive contexts in which they live.

The methodology of this research is steeped in the traditional ways of knowing and being of the Anishnaabe people, and specifically the context of the Beausoleil First Nation, my home community. This contextual knowledge is however deeply connected to and can be located within a larger Indigenous worldview, relevant to Turtle Island and beyond. Within Canada numerous Indigenous scholars have contributed to the development and articulation of Indigenous philosophy. It is important however to recognize that written academic scholarship does not mark the beginning of Indigenous philosophy, but only a particular acknowledgement of these ways of knowing and being.

Indigenous knowledge may reflect the interconnectedness between all living things and the land; the circular nature of time where the past, present and future are not separate and also includes traditional stories and those of colonization (Battiste, 2005; Brown & Strega, 2005; Dei, 2011; Kurtz, 2013; Weber-Pillwax, 2001; Stansfield & Browne, 2013). Although First Nations communities are diverse with unique languages and traditional ways of knowing and being, Overmars (2010) explains that there are commonalities including interconnectedness, holism and fluidity of living experiences that honors the voices of the ancestors.

In consideration of the concept of time for example, Leroy Little Bear contrasts the predominating and habitual linear approaches to time with Indigenous philosophies.

Unlike Westernized perspectives of time, Indigenous worldviews hold a cyclical view. As Little Bear (1977) articulates:

> Time is not a straight line. It is a circle. Every day is not a new day, but the same day repeating itself. There is no need to name each day a different name. You only need one name: day. This philosophy is a result of a direct relationship to the macrocosm. The sun is round; the moon is round; a day is a cycle-daylight followed by night; the seasons follow the same cycle year after year. A characteristic of cyclical thinking is that it is wholistic, in the same way that a circle is whole. (p. 14)

The circular, cyclical and wholistic philosophy extends and envelops all thinking where the quill box and its birch bark, porcupine quills and sweetgrass are of the land that belongs to all. Unlike the conception where land is only for human beings, Indigenous worldviews extend that it belongs to all including the rocks, plants and animals (Little Bear, 1977).

Richard Atleo (2004) further describes the concepts of time in relation to storytelling. When stories were told the “evenings themselves could become an eternity that was not only timeless, unhurried, and nonlinear, but also spatially motionless” (Atleo, 2004, p.4). Where people joined to listen intently to the storyteller, values including helpfulness were taught. Atleo (2004) explains, “the value of helpfulness is a call to cooperate with the original design of creation, which is characterized by oneness, wholeness, interconnectedness, and interrelationality” (p. 14). The togetherness within the circle of family, community and the land is of significance to the quill box methodology that weaves living stories within the relational context of the seven grandfather teachings. Furthermore the quill box in its materials centre land as pivotal to ways of being and knowing.

Vine Deloria also prioritizes land and sacred places where tribal ways of knowing and being are intricately connected. Deloria (2003) tells us:

> This center enables the people to look out along the four dimensions and locate their lands, to relate all historical events within the confines of this particular land, and to accept responsibility for it. Regardless of what subsequently happens to the people, the sacred lands remain as permanent fixtures in their cultural and religious understanding. (p.66)

Land then is critical to all and is a continuum with a way of being and knowing. This is vital to self-determination and Indigenous methodologies like the quill box methodology need to assert this connectedness to land and place.

2.4 Relational Axiology

From an ethical standpoint, coming to know the worldviews of Indigenous communities and going about research as consistent with that worldview is imperative. Research methodologies that emerge from the community’s worldview and culture are necessary as they counter colonization and are solely directed to benefit the community and larger community. As Hart (2010) explains the worldviews of Indigenous peoples emanate from the close proximity and being with the land that is sacred. “Key within a relational world view is the emphasis on spirit and spirituality and, in turn, a sense of communitism and respectful individualism” (Hart, 2010, p.3). In this depiction, the relational community becomes foundational where everything is connected, to the living, non-living and spiritual and within the harmonious cycles of creation. At the core, it is being bound to families and communities where individual expressiveness is also highly respected as furthering the needs of the community.

From this, it may be realized that the concept of relationality interlocks with axiology. In relationality, we are interconnected within the family, community and beyond, we are accountable to maintaining this relationship, which in turn nourishes us and guides us (Wilson, 2008; Hart, 2010). Barton (2004) also explains Indigenous relational ways of being as reflecting a circular pattern. Rather than the emphasis on individual knowledge, knowledge is shared and interconnected within the cosmos and all of creation (Wilson, 2008). "It is with the cosmos; it is with the animal with the plant, with the earth that we share this knowledge" (Wilson, 2008, p. 56). The ontology embraces being one with the land and all of its parts that are all relational versus domineering the land for personal benefit. Knowledge then embraces the whole, from both living and non-living entities to the grander cosmos and back again, a circular interconnectedness. The sacred circle embodies the whole sphere where all is interconnected (Barton, 2004). As foundational then, a relational ontological worldview is central to all research, methodologies and education that are to benefit Indigenous persons and communities. Relational ways of being may be represented through linkages with the living and nonliving, the conscious and unconscious. A full and good life or Bimaadiziwin as spoken in the Ojibwe language, entails that one lives the Seven Grandfather Teachings that are connected through all things including the rocks, the trees and everyone. The Seven Grandfather Teachings of wisdom, love, respect, bravery, honesty, humility and truth signify relational ways of being. "Truth is to know all of these things" (Native Women's Centre, Aboriginal Healing & Outreach Program, 2008, p. 5).

Figure 5 - Relationality: Powwow Beausoleil First Nation, Picture taken by Mary Smith (2015)

2.5 Methodology

Through the analogy of a sweetgrass and porcupine quill birch box actually made by an elder from my community, the methodology of this research encompasses Indigenous traditions that speak to my background within an Indigenous family and community. The sweetgrass and porcupine birch box is a circular container where the walls and bottoms of this container are made of birch bark and bound through a weaving of sweetgrass that holds the walls to the bottom. The lid is a beautiful flower made of different colours of porcupine quills surrounded by intertwined sweetgrass.

In this representation, the sweetgrass that is woven together represents the close knit and heartfelt relations and ancestors that continue to guide us through difficult times in illness and health. Wiingash is the Ojibwe word for sweetgrass and is like the long, warm beautiful smelling hair of our Mother Earth. The braided and woven strands signify the way the mind, body and spirit are not separate but are all woven intricately together. This weaving may also be likened to storytelling that brings the people together to follow the grandfather teachings of wisdom, love, respect, bravery, honesty, humility, and truth. The sweetgrass or wiingash as one of the four sacred medicines is also a reminder of the three other sacred medicines and for this reason are connected to the quill box methodology. The other three medicines in the Ojibwe language are known as maskodewashk, kiizhik, semaa or sage, cedar and tobacco respectively ("Anishnaabeg Bimaadiziwin," 2015). Sage is often involved in healing and cleansing. Through smudging or burning of the sage, the sage is wafted around like when washing oneself, over the head and body to remove the negativity and replace with kindness and goodness. Cedar may also be used to cleanse during smudging and may bring the mind towards positive feelings. Cedar and tobacco when ignited into a fire may bring the personal messages to the spirit world. Tobacco is the primary gift that gives thanks and communicates with the creator. It is given first by laying on the ground before other plants are picked or harvested. Tobacco, sage, sweetgrass and cedar represent the four directions ("Anishnaabeg Bimaadiziwin," 2015).

The birch box is the delicate and versatile strength that may come to mean the ability to transform and see new perspectives. Together the birch bark and the sweetgrass, a sacred medicine, symbolize all earnest and good things and healthful ways of living. When the sweetgrass is smelled the beautiful scent can only bring positive thoughts that cast away the dark lonely images. The porcupine quills represent the spirit animals and the clans that create a purpose and direction through our living within our families and community relations. The four points of the blackened flower quills signify the four directions further reinforcing the interconnectedness and guidance through the land and mother earth. The circular shape is that of the universe and father sun. Inside the box in the open space underneath the lid is the space that contains the dreams that come to us in our sleep and visions that behold our collective paths, destinies and the unknown mystery. The sweetgrass and porcupine quill birch box then captivates a perspective of Indigenous Knowledge, a paradigm that offers the ontological and epistemological ways of being and knowing, relational axiology, storytelling and dreaming.

In 2016 I attended the annual health fair in my community. This was also part of my volunteer work with the Kidney Foundation of Canada. I provided an information booth about kidney health, prevention of kidney diseases and health procedures including dialysis and kidney transplantation. This occasion offered a happy time to hug and chat with many of my relatives and elders. During this event I provided an informal presentation where I spoke again about my story of kidney transplantation. Given our relational community, many were already very familiar with my story and my family circumstances. Community members asked about my present activities so I described the quill box methodology. One of the elders who has made quill boxes commented that this seemed like a good way to help those with kidney disease (V.S. Smith, personal communication, July 27th, 2016). Everyone seemed interested and this informal get together exemplifies how storytelling and conversation happens within the community setting.

Learning from the elders is key to an Indigenous Methodology and very relevant to the conception of the quill box methodology was an interaction that I had with elder Basil Johnston at a Pow Wow in Midland, Ontario in 2012. In close proximity to the dancers with their beautiful regalia and the heartbeat of the drumming ceremonies, stood Basil quietly underneath a tree. At his side was a table full of books stacked high that he had written over the years. My memory is etched with meeting this most intelligent and articulate elder who passionately expressed to me the vital importance of traditional stories and their inseparability from language. The language expresses the Indigenous Knowledge and worldview where the trees, rocks and mountains are living and in the Ojibwe language have philosophical meanings (Johnston, 2013).

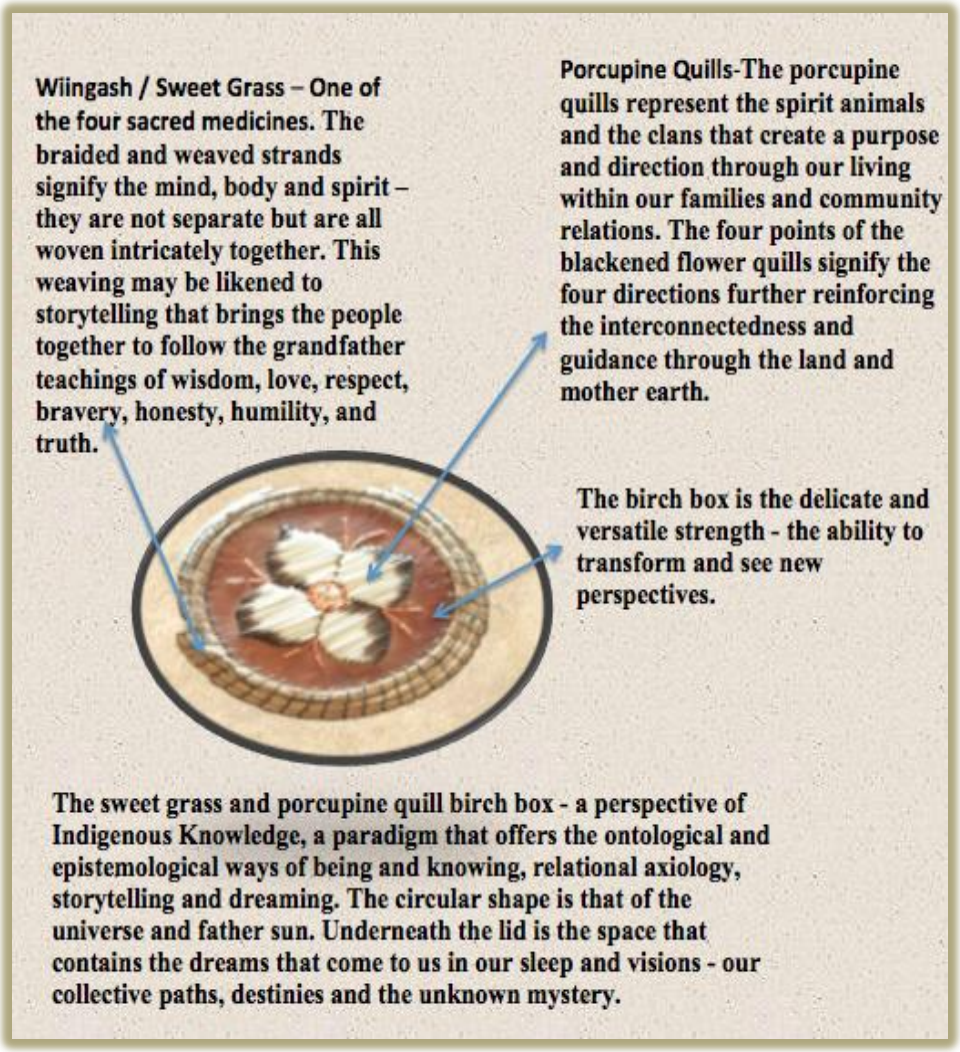
> Herein, I submit, is the nub and the rub. Without the benefit of knowing the language of the Indian nation that they are investigating, scholars can never get into their minds the heart and soul and spirit of a culture and understand the Native's perceptions and interpretations. (Johnston, 2013, p. 3)

Language then becomes the core. As Johnston (2013) exemplifies through the word Anishinaabe to identify the Ojibwe people also had meanings of fine and of good intention. Linked with the story of Nanabush who was full of good ways, the people had a sense of pride, strength and connection to the community (Johnston, 2013). In this sense, all that makes up the quill box is also linked with traditional stories that have multiple meanings to guide and offer purpose and direction.

> To understand the origin and the nature of life, existence, and death the Ojibway speaking peoples conducted inquiries within the soul-spirit that was the very depth of their being. Through dream or vision quest they elicited revelation-

> knowledge that they then commemorated and perpetuated in story and re-enacted in ritual. But in addition to insight, they also gained a reverence for the mystery of life which animated all things: human-kind, animal-kind, plant-kind, and the very earth itself. (Johnston, 2008, vii)

All the elements of the quill box come from the earth our mother, who possesses everything; it is not the people who possess her the earth. "The metamorphosis of naturally occurring materials into carefully crafted objects is at the centre of every artwork; it speaks to our human capacity for transforming the world" (Jensen, 1996). Mino-nawae-indawaewin, meaning "to live in harmony with the world and within one's being" is the guiding philosophy (Johnston, 2010, p.13). The connection to the land occurs through the traditions, ceremonies, sacred stories and craft or artwork such as in the making of the quill box. Women have been making quill boxes dating prior to European contact (Cole, 2009). This occurred in between all the other tasks required to survive including child bearing and rearing. During these times the craft makers of the quill boxes may have worked together with other craft makers, or taught their children or fellow community members how to prepare and make the quill boxes. This time spent together afforded warm bonding and strengthening family and community ties. It would also provide opportunities for story telling and learning from the stories being told. Throughout the storytelling, humour often shines through and laughter lightens the mood creating a happy perspective and an enjoyment of life. Craft makers would share their learning from life experiences while working away creating beautiful designs that were often expressions of the magnificence found in nature or forms seen in dreams. In the past all this happened through speaking the Ojibway language. The quill boxes are a manifestation of traditional living and knowing and a peaceful and fulfilled life. Today the art of making the quill boxes is still occurring in the community and workshops have taken place for the youth (A. Monague, personal communication, April 27th, 2017).



Wiingash / Sweet Grass – One of the four sacred medicines. The braided and weaved strands signify the mind, body and spirit – they are not separate but are all woven intricately together. This weaving may be likened to storytelling that brings the people together to follow the grandfather teachings of wisdom, love, respect, bravery, honesty, humility, and truth.

Porcupine Quills-The porcupine quills represent the spirit animals and the clans that create a purpose and direction through our living within our families and community relations. The four points of the blackened flower quills signify the four directions further reinforcing the interconnectedness and guidance through the land and mother earth.

The birch box is the delicate and versatile strength - the ability to transform and see new perspectives.

The sweet grass and porcupine quill birch box - a perspective of Indigenous Knowledge, a paradigm that offers the ontological and epistemological ways of being and knowing, relational axiology, storytelling and dreaming. The circular shape is that of the universe and father sun. Underneath the lid is the space that contains the dreams that come to us in our sleep and visions - our collective paths, destinies and the unknown mystery.

Figure 6 - The Sweetgrass and Porcupine Quill Birch Box - Wiingash gaaway wiigwaasi-makak

2.6 Methods: Storytelling, Circles and Dreaming

Dreams and sharing circles become the emerging methods that emanate from the sweetgrass and porcupine birch box where the stories of life ceaselessly transform and unfold. As will be discussed in the following section, these emerging methods from the methodology may yield the *living stories* of persons that are rich dialogues interconnecting culture, history and health. In 2010, Dr. Cynthia Wesley-Esquimaux, an Indigenous scholar and educator, expresses Indigenous stories as deep narratives that unearth the devastating histories and traumas of the past in the article, Narrative as Lived Experience. “Expressing narrative as lived experience has been shown by Indigenous healers and authors to be one very powerful tool for that desired change” (Wesley-Esquimaux, p.56). In the sweetgrass and porcupine quill birch box methodology, storying this living experience is different than the interpretation of the words ‘lived experience’. The words, *living story*, enable the meaning that living experience is beyond that of being lived but continues through the past, into the present and beyond, is not linear but transforms in relation to all living and non-living immersed within the cosmos. This speaks to a living story with no beginning or ending, like a web that continues to spin, linking with ancestors and majestic trees and mountains, living and breathing outside the European concept of time. With a methodology that speaks to the methods sharing circle and dreams, the living story then transpires from and through all of these methods to express the methodology rooted within an Indigenous way of being-and-knowing. The sweetgrass and porcupine birch box is filled with living stories.

Emerging from an Indigenous paradigm and my situatedness within a First Nation community, the sweetgrass and porcupine birch box compels methods that embrace a relational axiology. “The relational dynamic between self, others, and nature is central” (Kovach, 2010, p. 42). Storying conversations, dreams and sharing circles are considered as culturally acceptable ways of building knowledge and aligning with an

Indigenous paradigm (Marsden, 2004; Hart, 2010; Kovach, 2010; Wilson, 2008). Emerging from storytelling interchanges, the sweetgrass and porcupine quill birch box methodology is congruent with methods that involve storytelling conversations, sharing circles in which persons involved may freely and openly share their dream stories and interpretations. Storytelling, circles and dreaming are considered as methods that are intricately interwoven together. The circle must have the story and the story must have the dream. Storytelling, circles and dreaming are ingredients that come together to express Indigenous Knowledge.

Storytelling

Storytelling is flexible in that it allows the participant or storyteller and researcher to make their own story in their own personal way (Thomas, 2005). "Sharing one's own story is an aspect of co-constructing knowledge from an Indigenous perspective" (Kovach, 2012). A story can also be thought of as an offering or a gift in the Anishinaabe tradition (Doerfler, Sinclair and Stark, 2013). In this depiction, it may be realized how the story can strengthen relations, further bonding and connecting us at the heart thereby demonstrating relational accountability (Wilson, 2008). The process of storying in its telling and making, fits with the "dynamic characteristics of conveying and creating and re-creating identity" (Doerfler, Sinclair and Stark, 2013, p.153). Through storying then, identity may be strengthened and restored.

Kovach (2012) goes on to outline the responsibility of the researcher once participants agree to share their story. Transcripts need to be reviewed and approved by participants. Putting the oral story into text has its challenges as described by Thomas (2005). "Will the voices be heard? Will the voices of the storytellers be edited?"

(Thomas, 2005, p. 242). In this regard, Kovach (2010) brings forth the conversational method that nurtures and supports the oral nature and relationality inherent to storytelling and is also employed within qualitative research. Although decolonizing in its purpose, Indigenous methodologies such as the conversational method do not emerge from the transformative western paradigm that "centres the settler discourse, whereas an Indigenous paradigm centres Indigenous knowledges" (Kovach, 2010, p. 42). From another angle, Wilson (2008) explains, "as long as the methods fit the ontology, epistemology and axiology of Indigenous paradigm, they can be borrowed from other suitable research paradigms" (p.39). Participant observations, interviews, focus groups utilizing talking or sharing circles are some of the methods that Wilson (2008) delineates as emerging from an Indigenous paradigm.

Storying methods have also been described by Walker, Fredericks, Mills and Anderson in 2014 in their account of yarning methodology that emanated from the Australian Indigenous peoples. Yarning involves story sharing through conversation. This method goes even further in that it is linked with spirituality, cultural ceremonies and promotes relationality amongst the people. The method is deliberately comfortable and relaxed unlike the formalized and structured interview and it occurs within a culturally safe setting. Elders participate in guiding the process and participants self-select where all have input into the direction and flow of the research. Food was often present at the community gatherings for participants and elders. Permission was received from the involved Indigenous communities and mainstream university ethical protocols were followed (Walker et al., 2014).

Circles

A talking or sharing circle involves persons sitting in circle that signifies “the holism of Mother Earth and the equality of all members” (Wilson, 2008, p.41). In the same path of the sun from east to west, a feather from an eagle or another object of special significance such as a stone is circulated allowing each person to take turns speaking from the heart. Out of respect, others do not speak while the person who is holding the special object is speaking authentically and sincerely. The object may be circulated around four times but this depends on the circumstances (Wilson, 2008). The participants of the sharing circle will often speak through conversations with many stories that may even share dreams linked to stories. The overlapping conversations, stories and dreams may weave together as in the strands of the sweetgrass of quill box where interpretations and meanings unfold within the listeners that interlink to their own experiences and dreams.

Healing circles often occurred in my community where we would sit together in a circle and vent the anguish, frustrations and hurt felt in our lives. At the start of the circle smudging often occurs that further prepares and cleanses the spirit to embark on this healing transformation. Everyone has a turn to speak where a feather or similar symbolic item is held to designate that only the person holding this item may speak. This object also represents our connection to the land (Lambert, 2014). Tears and hugging each other in support may occur. Through this there is the connecting of hearts where we gather strength to continue and work hard to make life good again for our loved ones and community. The healing circle is a place where great hardships may be revealed and the love from everyone’s heart embraces the hurt and pain of the person speaking. Through this process the participants may feel a great burden is lifted off their shoulder.

A healing circle may be considered a journey to healing where in the circle with others the stories and traumas of life are shared within a safe space. Sharing one's life story continues to be a vital necessity in traditional healing (McCabe, 2008). The stories have incredible and far reaching meanings, like the concentric rings that form from a stone tossed into tranquil waters, they continue to teach and inspire (Sinclair, 2013).

Dreams

In the circles, dreams experienced while sleeping may also be shared. The dreams may be thought of as connections to the spirit world and are regarded very seriously. George Copway or Kah-ge-ga-gah-bowh was an Ojibwe who shared some of his dream experiences in his writings back in 1863.

> Dreams, too were much relied on by our nation. They thought the spirits revealed to them what they were to do, and what they should be…good hunters, warriors, and medicine men…I was taught to believe that gods would communicate with me, in the shape of birds, animals etc… When I fell asleep in the woods and dreamed some strange dream, I felt confident that it was from the spirits. (Copway, 1850, p.43)

Similar to Indigenous cultures in Australia, dreams are linked with the spirit domain and are not independent of the entire sphere of cultural ceremonies (den Boer, 2012). An elder once told me to always share my dreams as the dreams have great meaning and need to guide us in our actions throughout our lives. As alluded to in chapter one, dreams are very meaningful within many Indigenous cultures and it behooves health care professionals to listen carefully to discussions of dreams with the persons being cared for (Smith, 2014).

Dreams link with Indigenous ontologies and epistemologies in that the dreams express our self-perceptions, our being and thus shape our knowing (Hart, 2010). Goulet (1993) explains it is not enough to learn the language of the community but it is vital to learn the customs, tradition and to engage in the dialogical interpretation of dreams. “Indeed the Dene Tha held that it was only in coactivity with them in their rituals that I would gradually develop an appreciation for their inner dynamics and their many levels of meanings” (Goulet, 1993, p.181). In Goulet’s fieldwork with the Guajiro of South America and the Dene Tha of Alberta, Canada, animals were frequently experienced within dreams. With the Guajiro, the human being may be an animal, for example a bull may represent a man. The Dene Tha Elders described that dreams may be aided by spirit animal helpers that empower Elders to travel great distances (Goulet, 1993). Similarly, den Boer (2012) also explains that for “Indigenous people, both the spirit and the animal societies do not differ much from human society and are thus considered equal” (p.194). Lopenzina (2015) explicates the interconnectedness and entwined dream and waking states within Indigenous cultures did not distinguish between the supernatural and reality that are reflective of a Westernized mindset. Furthermore, Dawn Marsden of the Mississaugas of Scugog First Nation explores dreams as a research method (Marsden, 2004). Marsden (2004) shares the following:

> To validate dreaming as a research tool, we must remember that dreaming is where we symbolically process, synthesize and resolve the information, questions and experiences that we have had each day, with the understanding we accrued so far, to produce understanding ‘new to us’. (p. 54)

Dreams then have the potential towards discovery, new knowledge and making meaning of life and circumstances. A person's dream may guide them to action and even their families and communities. Sharing dreams with others brings people together; strengthening the social connectedness that furthers supportive community networks and sustains resilience. Moreover, dreams are consistent with the relational ethic, where dreams shared within the community may guide persons away from harm or towards nutrition. For example, a dream may lead to where an animal may be hunted to feed the family and community and provide treatments for illness (Kaniuekutat, 2009; Marsden, 2004). As essential to well-being it may be appreciated and valued how dreams are of paramount importance within Indigenous ontologies. Furthermore, dreams potentially may be realized to foster Indigenous research methodologies that emerge from Indigenous worldviews that necessitate relational accountability to the community.

Kovach (2012) interviewed Cree scholar, Michael Hart, and describes dreams as a method within the Indigenous methodology where dreams provide meaningful guidance through the course of one's life.

> Let's say I dream about a smoke lodge, a dream about a particular aspect of a smoke lodge, the way you have to go to the smoke lodge. The dream in and of itself has informed me, but the knowledge process is just more than me having that dream. It is more than me taking that dream and talking with an Elder about it. It includes that process of doing whatever I have to do for that dream to become reality…[t]here's a longer process that needs to be involved in bringing the dream to life. It's already alive, but bringing that dream into this world. So that whole piece, how you come back, how you ended up home. To me, that is

> speaking about the methodology…[t]he dreaming would almost be part of the method. (Kovach, 2012, p.70 -71)

From this compelling interview, dreams emerge as a method. As within the quill box methodology, dreams have a central place. Along with storytelling and within sharing circles, dreams further the living stories that emanate from the sweetgrass and porcupine birch box methodology.

This chapter has offered an in depth description of the quill box methodology and the methods involved. Although the quill box and Indigenous Knowledge is both ancient and contextual, it's portrayal as a methodology for this study is new. Developing a new and innovative methodology has become an immense undertaking where the learning through the quill box parallels the infinite knowledge within the medicine wheel. In this construal the decision to develop on the basis of needing a contextual methodology consistent with both the researcher and community's history and ways of being and knowing became the priority. As Lambert (2014) explains the medicine wheel is used as a methodology, however, the medicine wheel is not generalizable to every Indigenous person or community and its usage varies widely. The quill box methodology then is unique and flows from the interpretations and understandings between myself, the writer of this dissertation in conjunction with the community. This has required a deliberate attempt to break free from the entrenched patterns of utilizing other methodologies with their requirements for testing and rigour. However, this was felt to be necessary knowing the mistrust towards research and the few Indigenous methodologies available within the formalized academic setting. In the following chapters, the quill box methodology will be exemplified and illuminated as a methodology suiting an Indigenous community.

Chapter Three: Research

In this chapter, the research is described under specific headings that align with the proposal dissertation that was construed in conjunction with the Supervisory Committee at the University of Victoria in 2016. The proposal dissertation was then utilized in the ethics application that received ethics approval in March 2017 (Certificate of Approval- University of Victoria, Ethics Protocol Number 17- 030).

3.1 The Research Questions

Two research questions unfolded during the development of the Proposal Dissertation and are as follows:

1. What are the living stories of people with kidney disease within a First Nation community?
2. How does the sweetgrass and porcupine quill birch box methodology foster the interpretation of the living stories in relation to kidney disease?

3.2 Aims and Proposed Benefits

The study sought to further engage with the living stories of Chronic Kidney Disease (CKD) in a First Nation community. Through living stories the contextual and cultural expressions of CKD are voiced. Listening to the voices centers cultural safety that acknowledges the historical issues of oppression and colonization and prioritizes Indigenous knowledge. Critical for health care providers and ethical health care is to listen to the voices through living stories as described in the methodology section. The need for research that seeks to discover the living stories of First Nations peoples offers to explicate the intricacies of CKD. This is necessary for determining appropriate, meaningful and sustainable actions. I felt it was highly important to initiate this study given the onerous burden of suffering from chronic kidney disease (CKD) within First Nations and the lack of existing research. This research aims to further understanding of the experiences of CKD within First Nation communities. Through the living stories culturally rooted ways of being intersecting with historical colonial systemic issues may be identified towards further action to benefit the community.

With regards to the second question and in addition to what has already been explained in the methodology section, it was essential to engage a culturally safe positioning as fostered by the quill box methodology that acknowledges the historical issues of oppression and colonization and Indigenous knowledge. This is critical for health care providers to learn for ethical health care to be actualized. The need for research that seeks to discover the living stories of First Nations peoples with CKD offers to expose the intricacies of CKD issues, issues that must be thoroughly understood if appropriate actions are to be taken. Living stories are not something that can be found but are fluid, relational and rooted within Anishnaabe ways of being and knowing. Through this approach the methodology moves toward the increased representation and understanding of First Nations experiences with Chronic Kidney Disease (CKD) through an Indigenous methodology that prioritizes respect and engagement of Indigenous ways of knowing and being.

Benefits for participants as described in the University of Victoria (UVic) Human Research Ethics Board (HREB) included to share support and knowledge, express our stories, what they mean to us and inform ways to make things better, help the health care professionals to better care for us by understanding what it is like for us and what we have to go through, voice and be proud of our beautiful culture, lead to and be a stepping stone to bigger initiatives, form strong bonds and great friendships, learn about kidney health care, transplants and dialysis and learn about ways to safeguard our health and prevent kidney disease.

3.3 Locating myself as a Researcher

I am a community member and kidney donor with relations with CKD as well as being a Nurse Practitioner. The participants and myself are members of the Beausoleil First Nation in Ontario and they reside within the southern Georgian Bay area that includes Christian Island and Cedar Point. This community was of interest as I am very acquainted with the extent of Chronic Kidney Disease within this community through family who are members of this First Nation community and who either have kidney disease, have been on dialysis or have had kidney transplants or are awaiting transplant. I have vested and heart felt community-bonded interests in bringing forward further understandings of the experiences of kidney disease. This comes from my personal experience and familiarity with the community cultural ways, traditions and protocols and the increasing prevalence of kidney disease amongst Indigenous groups. Through this awareness and understanding, ways to improve the circumstances surrounding kidney disease may be realized.

3.4 History and the Land of the Beausoleil First Nation

To further understand the participants it is helpful to be acquainted with the history and the land of the Beausoleil First Nation or Reserve 30. First it is important to note that the name Christian Island comes from the settlers and stems from a colonial past under religious dominance throughout history. This island is also commonly known by the people as Chimnissing, meaning big island in Ojibwe. There have been other names for the island as well including, Gchi Nme Mnissing, meaning the great Sturgeon Island (Betasamosake Simpson, 2013). Gahoendoe is another name that arises from when the Huron and Jesuit colony first inhabited the island over 300 years ago. The community express their enduring love and connection to their island home in many ways. Below is a picture that conveys this intimacy with the island.

Figure 7 - Drawing on Chimnissing Home-Picture taken by Mary Smith (2015).

The visceral connectedness to the land cannot be emphasized enough. George Copway was also an Ojibwe person as are the participants in this study who demonstrate this profound attachment to the land.

> I am one of Nature's children; I have always admired her; she shall be my glory; her features-her robes, and the wreath about her brow-the seasons-her stately oaks, and the evergreen-her hair-ringlets over the earth, all contribute to my enduring love of her; and wherever I see her, emotions of pleasure roll in my breast, and swell and burst like waves on the shores of the ocean, in prayer and praise to Him who has place me in her hand. It is thought great to born in

> palaces, surrounded with wealth-but to be born in nature’s wide domain is greater still! (Copway, 1850, p. 17)

Many moons ago, back in 1648 the Jesuit Priests with the Indigenous group known as the Hurons fled to Gahoendoe to escape the Iroquois warfare. Unfortunately, the winter of 1649 brought mass starvation and disease to the early island community. The survivors fled to Quebec City in 1650 and some of the Hurons went to Manitoulin Island. Then in 1856, Chief Aisance led his band of Ojibwe people to Beausoleil Island (Schmalz, 1991) after being driven off the Coldwater settlement. The Coldwater settlement was once the home to the Chippewa Nation of Lake Huron and Lake Simcoe as had been established by Lieutenant Governor Colborne in 1829. Unfortunately survival was not possible on Beausoleil Island. The band now referred to as ‘Beausoleil’ then relocated to Christian Island. Originally the bands Beausoleil, Mnjikaning (Rama) First Nation and Georgian Island were part of the Chippewa Nation of Lake Huron and Lake Simcoe. The three bands would form the Chippewa Tri-Council (Schmalz, 1991).

The Tri-Council would become involved in one of the largest land claims concerning the relocation of the original settlement in Coldwater, Ontario. In 1836 the Coldwater reservation was taken in a manner in which the Chippewa were not in full understanding and were misled. This resulted in the dispersion of the people to the remote and often isolated areas where they remain today. However in 1991, the Tri-Council submitted a land claim with regards to the Coldwater-Narrows Reservation that would also involve the Chippewas of Nawash (Riedner, 2012). This land claim was settled in 2011 and now continues to support the Beausoleil First Nation Nookmis community projects. Nookmis meaning Grandmother in Ojibwe represents the initiatives that bring meaningful benefits to the people. Many of the Nookmis meetings in the community involve and engage many community members and elders to foster community driven initiatives.

The reserved land of the Beausoleil Fist Nation is comprised of Christian Island, Beckwith Island, Hope Island and Cedar Point. The islands are located in southern Georgian Bay in Ontario. The total registered population of approximately 2,492 resides on Christian Island, Cedar Point and off reserve with about 643 residing on the island (Indigenous and Northern Affairs Canada, 2017). The distance between Christian Island and Cedar Point where the main passenger and vehicle ferry docks are located is about five km. (See maps following.)

Figure 8 - Image from ferry at Chimnissing, Picture taken by Mary Smith (2015)

Figure 9- Islands of the Beausoleil First Nation

Source: https://www.google.ca/maps/place/Christian+Island+Indian+Reserve+No.+30,+Christian+Island,+ON/@44.8466556,-80.2422667,19486m/data=!3m1!1e3!4m5!3m4!1s0x4d2ac65589c5e019:0x3e171a21400a5481!8m2!3d44.8316783!4d-80.203564

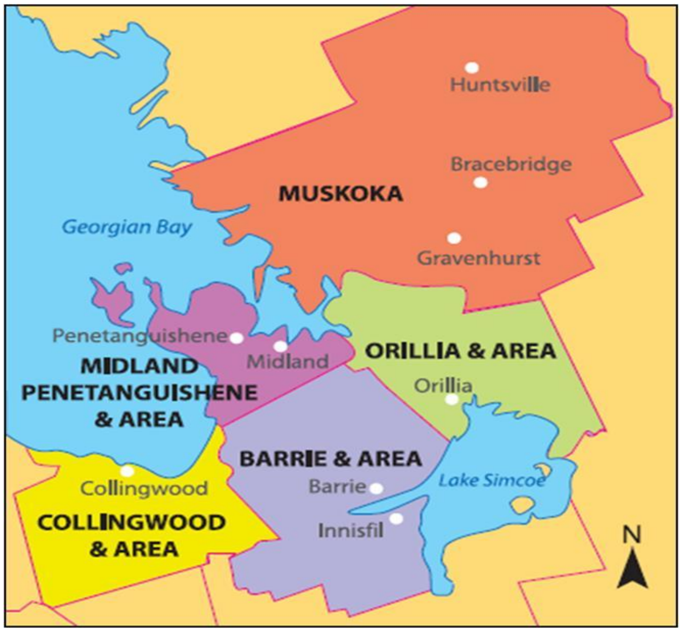


Figure 10 - Proximity to Mainland Services, Source: NSM LHIN

3.5 Community Consultations and Recruitment

Opportunities to consult with the community occurred in conjunction with the Chief and Council's Nookmis proposal fairs that occurred in December 2016 and January 2017 where up to 80 community members of the Beausoleil First Nation attended and provided widespread community support for this endeavor. This support was further supported by the community's Chief and Council who oversee all Nookmis activities. The proposal fair involved several other community projects where information was also presented. The gathering offered free transportation, lunch and some door prizes for all participants and was advertised through the community newsletters.

At the first consultation meeting in December 2016, I asked for those who knew someone with kidney disease to put up their hand. Almost everyone who had attended this event raised his or her hands. This occasion allowed for group and individual discussions to explain the proposal and the activities involved. Over 30 community members signed a list at this meeting expressing their interest in participating. The second meeting in January 2017 also allowed for more community members to express their support and learn about the proposal. An audience of close to 100 people attended. I spoke to many community members at this event who described their particular health situations related to kidney health. Both events were advertised through the community newsletter that is available in print and online. From the list, starting with the first name, I contacted each potential participant by phone or email. The proposal's selection criteria guided the process, namely the participants had to be aged 19 or over, would identify as Indigenous with kidney disease or having a relation to a community member with kidney disease. Three persons declined to participate due to their personal schedules. When ten persons from the list had been selected as per the proposal's selection criteria, I then met with participants where consent was granted. This occurred after ethics approval was obtained in March 2017. During the consultation meetings the proposal was nicknamed the 'Kidney Circle' in light of the sharing circles to occur.

Participant Description

Participants were the Beausoleil First Nation community members who are of Ojibwe and Potawatomi origin. There were ten participants, who consented as per the form developed in accordance with the UVic HREB, Application for Research Ethics Approval for Human Participant Research. (See Consent Appendix A). Seven women and three men were recruited. Of the seven women, one woman was between the age of 60 and 65, two were between the ages of 50 and 55, two were within the 40 to 45 age range and two ranged between 20 and 30 years of age. There was one elder man between the age of 60 and 65 and two men both in their early 50s. Two of the participants were receiving hemodialysis, one was on peritoneal dialysis and another had a kidney transplant. Of the ten participants six had Type 2 Diabetes Mellitus (T2DM) and hypertension (HTN). Two of the participants had been told they had CKD and the remaining four participants did not have CKD but had family members with both CKD and ESRD. All participants knew someone in the community who had been on dialysis or had a family member or relative on dialysis in the past.

Community Advisory Committee

The community advisory committee consisted of three persons from the community, one elder and two other community members. This was a helpful group that came together in a friendly and informal way, meeting periodically in the community coffee shop. Three meetings occurred before participant selection to familiarize the committee with the proposal, consent and UVic HREB approved application and to coordinate with ongoing events and the community meeting. Feedback enabled the assurance that the processes as set forth were in accordance with the community and adhering with the principles of ownership, control, access and possession where the ultimate purpose is to enhance the health and well being of the Indigenous population. This is in keeping with the need to bring forward positive action, reducing the suffering from kidney disease and healing and recovering through traditional knowledge. It was important to have the feedback of the committee members as they also had extensive involvement with kidney health issues themselves and were very knowledgeable of the specific community circumstances including transportation challenges with the geographic island setting. In addition, the members were keen on the quill box methodology and enjoyed describing their perspectives within the unique cultural context of the community. The community advisory committee members are also hoping to continue as peer support volunteers. This is similar to the Peer Support Program offered through the Kidney Foundation of Canada.

Sharing Circles

In addition to the previous description as outlined within the methodology section, the sharing circles offered an opportunity for those who preferred the company of others given the relational perspective of cultural ways of being. It was explained to the participants that they may feel stressed when sharing their stories if their stories brought forwards experiences of pain or trauma. If this was the case or if participants felt unable to continue participants would be supported and connected with community services offering ongoing assistance as needed. This is further described in the consent, see Appendix A. Despite this offer none of the participants left any of the circles. The sharing of stories also created a supportive setting among participants to share similar experiences as well as to feel strengthened through the cohesiveness of the group. Voicing one's concerns offers support in that the person's experiences would be heard and acknowledged. Kidney disease can be a frightening experience when exposed to procedures such as dialysis and transplantation. The sharing circles though, offer support and learning through one another and this may have lessen some of the fears and offer comfort in knowing that one is not alone in their experience.

Three sharing circles occurred within the period of May 2017 on weekends, days and evenings to accommodate for those who work or are on dialysis schedules. Each session began with prayers, smudging and acknowledgement from an Elder participant. Aligning with traditional ways, the Elder participant was gifted with tobacco and received a small gift as an honorarium. Three community members required transportation to and from the circles. The first session reviewed what had also been explained during community consultation events, and through the consents as well as the guiding questions of the research encouraging the living stories of kidney disease. The participants in the circle were warmly welcomed to share their stories and dream stories. During the sharing circles the participants rotated from the east to west in a clockwise fashion to allow equal opportunities to express themselves. After the elder participant spoke and refreshments were provided, the circle began with interactive discussions where the participants passed around the quill box to each other. Similar to a talking stick the passing of the quill box signaled each participant's turn to speak, allowing everyone to share his or her stories.

The second sharing circle session continued in a similar way but allowed for more sharing of experiences or attention to particular stories and dreams and ideas that resonated from the first sharing circle. During the third session, participants were provided time to read over the transcriptions of the first two sharing circles. This enabled feedback for accuracy of the transcriptions. The final session also offered a time for closing feasting and celebration of our bonds and friendships formed. Food and refreshments were offered and several breaks occurred. The sessions lasted between two to three hours in length. This duration of time was in acknowledgement that some of the participants had physical concerns related to kidney disease and family commitments or had to catch the ferry for other scheduled commitments. The locations for the circles altered between the community health and senior centres and a private space was also provided within the community coffee restaurant.

3.6 Data Software and Analysis

The Atlas.ti program offered organization of the data that assisted in analysis and attention to emerging ideas. The central ideas were interpreted through the lens of the quill box methodology that focused on traditional knowledge. The software was helpful to organize the data that was interpreted through the quill box methodology that gleaned introspective contemplations towards participant living stories. Simonds and Christopher (2013) and Lavallée (2009) prioritize the protocol in maintaining the whole story. Segmented stories may be considered disrespectful where the unbroken story is to be honoured. The word 'theme' or 'theme analysis' may suggest the dissection of stories where a holistic approach to the stories is consistent with the quill box methodology. In this regard, whole stories as paragraphs rather than sentences or parts of a sentence were maintained to glean the underpinning meanings that together with other similar living stories from other participants formed patterns. This occurred naturally through the sharing circles where a participant's discussion would often be furthered by the adjacent participant who would then build on the former participant's comment in deeper ways. For example, when a participant spoke of dreams, the adjacent person in the circle would follow this flow of communication and speak to their own stories involving dreams.

Immersion with the data took lengthy periods and began with the actual listening to participants in the circle, followed by transcribing the stories, replaying the audio-recording and pausing to contemplate ideas and then reading and rereading passages while writing memos to provide cues of specific thoughts and insights into the meanings and significance in relation to kidney health within the context of culture and history. I kept notes as comments in the software to capture thoughts that occurred while reviewing specific stories in relation to other participant stories that enabled formulating of specific patterns that could be captured with word phrases. The word phrases revealed the patterns in the stories that became the titles of the living stories as delineated within the Living Stories section of this dissertation.

3.7 Data Confidentiality and Management and Ethics Approval

All data was stored in the password protected electronic format with the Atlas.ti software and word-perfect password protected documents. To help protect confidentiality, the recorded interviews and data did not contain information such as name, age or sex or other demographic information, email address or IP address.

Confidentiality of the participants and the confidentiality of the data was protected by password on the computer used solely for this research and was kept locked in a cabinet that was further locked in my office. Participants in the circle were asked not to share data in a way that connects it to particular participants in the circle. Please see also the consent in Appendix A for further details regarding participant confidentiality. Participation in this research was completely voluntary and there were no withdrawals.

Despite increasing academic acceptance of qualitative research, particularly in the discipline of nursing, this approach to research is scrutinized for its credibility and trustworthiness. I felt it was necessary to have ongoing participant and community feedback with regards to the transcriptions of the oral living stories to further credibility and trustworthiness. In keeping with this process, participants were asked to review or check the transcripts that contained only their own transcribed data. This required ten different files with each participant’s individual transcript. Through consistency with the principles of ownership, control, access and possession (OCAP), credibility and trustworthiness was also furthered where the data comes from the community and is for the community’s purpose and benefit. The concept of ownership is understood through a relational lens that holds accountability to the people, to build relationships to make things better (Wilson, 2008). Stories have always been shared to benefit the people. Similarly the living stories in this work are to benefit the community. In ownership the meaning is through the community context where the community directs the Chief and Council to engage specific persons or groups to be the knowledge holders. This aligns with stewardship concepts whereas to own knowledge leans toward westernized thinking. As Hanson and Smylie (2006) articulate:

> Traditional Indigenous thought supported the ideas of “stewardship” which meant that identified individuals, groups, families or communities were given the responsibility for carrying specific knowledge along with any rights or privileges that may accrue from holding the responsibility in a “good way”. (p. 15)

In this regard, as a community member and essentially as a designated knowledge holder, I was in a unique position to manage, secure and hold the data for the purposes of the community. This was a process that developed through the community consultation meetings, proposal and HREB application and approval. Control, access and possession are explained in this regard, where I would manage or control the data, including security or confidentiality as previously explained, that includes access and possession as directed for, by and with the community. All of this is also in keeping with the 4R’s that include respect, relevance and reciprocity and responsibility (Kirkness & Barnhardt, 1991). Valuing the community knowledge through the quill box methodology and involving and engaging community participation in everyway possible facilitates respect. This required more than just being involved in sharing circles and consultation meetings. Respect meant attending and participating in as many community events as possible including powwows, sweat lodges, smudging ceremonies, sovereignty day, health fairs, senior dinners and craft making events. The quill box methodology as previously outlined is inherently relevant to the community culture through its attention to drawing on Indigenous knowledge that delves deep into history including historical events. Reciprocity occurs through the sharing of knowledge and learning that occurs in consultation meetings, sharing circles and community events. In attending and organizing such events I was often able to share the story of kidney transplantation that stimulated conversations regarding acquiring further resources to learn about the process of organ donation. At the same time the activities that I was involved in provided enormous learning regarding Indigenous knowledge and societal barriers to health care. Respect, relevance, and reciprocity also involve taking the responsibility to attend to all matters including confidentiality and being continually engaged with the community beyond this specific project or academic timelines. From this it may be realized the manner in with OCAP principles and the 4R's are prioritized throughout this research and dissertation.

As previously discussed the process through ethics approval occurred following the UVic HREB Application for Research Ethics Approval for Human Participant Research. This began during the late fall of 2016 and extended into March 2017 when the Ethics Certificate of Approval, 17-030 was granted. The HREB application aligns with the Tri-Council Policy Statement, 2nd edition that includes Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada, 2nd Edition (TCPS 2). The TCPS 2 – Chapter 9 was developed in light of the OCAP principles and the colonial implications of prior research that lacked First Nation involvement. The OCAP principles were a political response to the prior TCPS that centered on self-determination (Campbell 2014; Schnarch, 2004; Smith, 2012). Through consistency with the OCAP principles, the 4R's and meeting the approval of the HREB, the research rigorously targeted community participation with the aim of the development and understanding of kidney disease and health care through the utilization of a culturally safe methodology.

Potential ethical concerns that emerged during the application approval process concerned that I had previously been a health care provider in the community. This necessitated the explanation emphasizing that I would not be involved in providing direct health care and any health care issues that arose would be referred to the appropriate health care practitioner available in the community. Another matter was the possibility of my being related to a participant, as this is a common situation in small communities where there are many relational bonds and relatives. The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2 (TCPS 2) explains:

> First Nations, Inuit and Métis scholars attached to academic institutions as faculty members, students or research associates are increasingly engaged in research involving their own communities, and sometimes their own family members. They are generally exempt from restrictions on physical access to territory or personal access to community members. However, as members of institutions that adhere to this Policy, they are subject to the ethical duty to respect community customs and codes of research practice when conducting research in their own local or cultural communities, and to engage the relevant community as required by this Policy. (Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humananities Research Council of Canada, & Medical Research Council, 2014, p.123)

This did not emerge as a problem, however had it been, it was acknowledged within the HREB application the requirement to further resolve this with the supervisory committee. Moreover, in line with the goals of self determination, the involvement of community members, who are researchers connected with academic institutions with vested interests in improving life for their fellow community members that are also family relations is of paramount priority. First Nation community members involved in academic universities become involved in research with the ultimate goal of benefiting their communities who are their family relations.

Chapter Four: The Living Stories

In this chapter the living stories come forward amidst sharing circles where the quill box flows from Anishinaabe izhitwwain. Within sharing circles the participants frequently made reference to and associated the symbolic meanings of the materials that comprise the quill box with ways of being and knowing within their contextual experiences of kidney disease. In listening to and transcribing the living stories central ideas emerged as the headings within this chapter, i.e. relational and cultural connectedness mitigates fears of disease and treatments; equitable access; racism in healthcare and dreams. The quill box enmeshes Indigenous knowledge and relationality, in that its materials link with Indigenous ways of knowing and being that permeate living stories that speak to kidney disease. In such living stories ways of being and knowing are pervaded with messages concerning cultural safety and equitable access.

Specifically to frame and organize, the living stories bring forth Indigenous knowledge through the participants' vernacular about the quill box and their sharing of dreams within the sharing circles. The living stories also express relationality reflexive of community attachments and equitable access that includes accessibility to organ transplants, dialysis and the involvement with Non-insured Health Benefits (NIHB) and cultural safety as racism in healthcare. In understanding the significance of the quill box materials and cultural expressions, meanings are found through recognizing that the materials imbue ways of knowing and being amidst a structured health care system that limits Indigenous participation. Meanings from the living stories connect through the quill box methodology in non-linear and in a circular ways, where all facets are involved including language, history and interconnections with the land.

The knowledge and wisdom bestowed within the quill box manifest as the living stories. As in the journey of crafting the quill box, the gathering of the materials of sweetgrass, birch bark and quills and weaving them with the hands to form a beautiful creation; the materials of the quill box are reflections of knowledge, of cultural ceremonies, history and life events. The living stories express meaningful insights connecting Anishinaabe-izhitwaawin with kidney health and together create whole stories linking the past with the present and future. Amidst Anishinaabe-izhitwaawin, there are oral stories, the language and a way of knowing being communicated. Basil Johnston conveys the oral stories in written form and the history of the "Anishnabeg" or Anishnawbe (Johnston, 2008, p. 163). Johnston shares:

> The story of our people does not end here. It goes on - it will continue to go on - and it is good, sometimes to stop along the trail in order to rest and look back…From the past and from our ancestors we have inherited a language harmonious to the ear, ceremonies edifying to attend, and traditions to be observed and continued. (p.167)

The living story is in symphony with the whole, the reflections of life priorities including the relational family and community, the history and present shaped through colonialism and the traditional ceremonies and ways of being and knowing. The stories speak to the strengths within a community bonded through a history of survival together, the relations, language and traditions. They also emphasize the injustices, the pain and stress that comes with the hardships endured through isolation in seeking health care that is accessible and understanding of community history, colonialism and culture.

4.1 Relational and Cultural Connectedness Mitigates Fears of Disease and Treatments

The quill box with its materials of porcupine quills, birch bark that are bound together with sweetgrass came to represent the crucial community relational bonds that offer critical support and survival through the difficulties associated with kidney disease and its treatments. One story explained:

> When I look at this [holds quill box], and see how everything is sewn so carefully together, I think of being with all of them [relatives], my grandkids and my sister who used to make these quill boxes, but now she can't do it as she can't see too well… so her sugar was really high, they kept telling her to go on dialysis and she wouldn't accept that she wouldn't take care of herself, now she's on dialysis, she had to carry air in a tank, she goes three times a week, we all help her as much as we can, try to bring her meals and get her out to the powwows.

Relational ways of being may be seen as a cornerstone to strong communities that have survived the ongoing historical assaults that have escalated in the degradation of families with associated poor physical and mental health. It may be felt through this passage how vital the family and relations are, the grandchildren that offer hope and ways to maintain essential cultural practices and traditions that represent the peace and beauty in nature as apparent in the artwork of the quill box. It is also recognized how there is so much fear of kidney disease and in this fear there comes a possible denial of the condition that may lead to poor self-care.

This relational connection continues in another participant's revelations where the fears emerge in seeing so many relations ill with kidney disease where feelings of despair come forward. This is counteracted with the hope that comes through the love of a child that may continue with inspirational and spiritual ways of cultural traditions. Home dialysis options such as peritoneal dialysis (PD) offers a way to remain within the community.

> I was really moody um…when they told me I need dialysis, at first I thought well so what I'll just die, we all die anyway, what's the point anyway; my auntie died [pauses] dialysis, now me, it was my daughter who made me smarten up, she said how I'm going dance, who's going to make my regalia if your're gone [laughs , pauses] then I knew I would have to try to stay alive on dialysis, I ended up choosing PD…um and have been doing it at night now for a few years, had an infection once and thought that's it or would have to start going for hemodialysis, I hated that idea, I need to be at home not to have to leave always to spend all my time away from home strapped to some machine facing death, but then I got better and could continue with the PD but I wonder how long I can go on…

Within the relational context the importance of being at home in the family and community surroundings emerges as a high priority where treatments that occur in the home setting are sought. Ceremonies such as dancing and the craft making involved offers a reason to continue living. The traditional activities provide direction and a sense of purpose.

Fear again transcends through a participant's recollection of discovering he had ESRD and would need a transplant, that is met with a family member's gift of organ donation.

> These quill boxes are strong, and made to last and that's how I feel about my kidney transplant. The beginning of March my white blood count went real low down to 8% but that's the only hiccup I had but they gave me something to bring it up and it has been fine ever since, they reduced my [medication]… it hit me like a ton of bricks [when first diagnosed], the Dr. phoned me on a Saturday, the Dr. phoning me on a Saturday? I said that's very unusual, told me that my kidney function was down to 11 %, told my wife and had a good cry, what are we going to do, we're going have to deal with it I guess but then my sister came along and said ok I'll give you one of my kidneys and I said ok but I made sure that it was ok with her husband and kids first, I said are you sure that's what you want to do and she said I already made up my mind, and said ok we'll get all the testing done and might not be sure if testing doesn't go alright, …I'm on the lowest dose of antirejection, another 15 years they will have an artificial kidney, remember to take your medications…

The strength of the relational bonds shine through where there is the family and community support of kidney donation. Close interpersonal relations make persevering the crisis of losing kidney function possible. Medications are emphasized in this participant's discussion that stress the vigilance necessary to maintain health and prevent rejection of the transplanted kidney.

Then an interesting perspective comes forward from another story in relation to Indigenous knowledge and traditions:

> That's why I see the Mashkikiiwinini [traditional healer in Ojibway]. You see like this quill box is a gift from the earth, everything it is made from comes from

> the earth, the birch tree, the sweetgrass, the porcupine are all from the land that gives us protection, a way to move on the water, medicine and food. We and all our people come from this earth and belong to it and together we made this box from the gifts of the earth. Our medicine does not separate us from the earth but it is connected to it and heals the mind, body and soul.

A deep interconnectedness to the earth ensues through all ceremonies, medicines, the artwork and the language where this umbilical like attachment to the land and its spiritual meanings pave the journey to a meaningful and good life. This is further echoed within the following story:

> I made one of these at the workshop. It's hard work, not easy, you have to prepare the birch bark, make it flat, it takes time, you need to find the porcupine quills, if you pull them out wrong they will break, better to do by hand [rather] then with pliers, you've got to get the sweetgrass, all that stuff during the right time and season, can take a few months or even up to a year, then it takes hours to do this; just like it takes a long time to get yourself strong again after stopping the drink, it takes a whole lot of love and support and understanding from the community, you can't get back easy when your soul is broken, you have to ask the creator for help, the body only heals when the mind does, you can't make the right decisions when you're messed up, I have been like this but I'm finally feeling strong again.

Here the words "love and support and understanding from the community" resonate to convey the meaning of the relational way of living. This interweaves with the making of a quill box and the difficulties and time it takes to heal the mind that must occur before the body can mend. The interconnectedness between art and the quill box as representing a form of Indigenous art interconnects with the land and the people that are intricately united. This is further accentuated with the following Elder's story:

> The grandfather teachings show us to give to each other and in that sharing is love that connects us all in the community, keeps us together, makes us strong. The earth shares with us the medicines from the plants, the food from the plants and animals, who are our spirit helpers and connect us in one big circle.

The circular shape of the quill box may also come to represent this relational way of being, in harmony with the all the circular spheres including the moon, sun and the earth and everything of it.

4.2 Equitable Access

Several of the stories spoke to the challenges associated with the travel to dialysis and their interfaces within westernized health care.

> Dialysis, I was on for six months and it was horrible because you live by their clock, that was the ultimate goal, a dialysis on the island, it was suppose to be, [the] Dr. was over here at one point to see if we could get a dialysis clinic because there were so many people on dialysis cause the thing is you don't need one machine you need two, cause you always need a back up.

At this point there is not a dialysis clinic in the community. Given the many community members who require dialysis and reside on the island it would seem that this should be a more accessible service. Presently the options for hemodialysis services include a satellite clinic located in the nearest town of Penetanguishene, Ontario. In order to get there, residents are required to take the half hour ferry and then an additional 30 to 40 minute drive. As there are limited seats within the satellite clinic, some persons requiring dialysis are required to travel to the main center located within the closest city, this can be at least a 60 minute or more to drive in duration. Travel time increases during inclement weather. In response to this description another story explained:

> Everything is hard here because we always have to go everywhere to get things done, if you need dialysis you have to go to [local town] if you're lucky but you have to wait for a spot there, then you have to start in Orillia, some are doing the dialysis at home but can be tough if you don't like needles or don't understand how to do it properly, one time I was late for an appointment because the ferry was off schedule cause they had an emergency, by the time I got to my doctor's the secretary said I would have to reschedule for another day, I was so mad, they just wouldn't even try to understand…

To further add to this expression of hardships that include transportation a participant began to depict the feelings of inequity, felt in relation to the ongoing issues associated with transportation and access.

> To me it's all about access, we got stuck out here on this island by them, now its our home, but because we are out here on an island they don't give us the same, like we don't have a hospital here, we have to cross the bay all the time in the worst hellish weather, people have died trying to fish to make a bit of zhoonyaa [money], just so we can have the same things they have on the mainland, we don't have what they have.

Resentment and feelings of unfairness revolve around the participant discussions that arise from the hardships experienced through the daily struggle in trying to access life sustaining treatments. The words “we don’t have what they have” express the dire situation where the historical displacement of Indigenous communities to geographically remote and isolated areas has created extreme hardships and the inequitable provision of health care.

4.3 Racism in Healthcare

Several of the stories described views regarding healthcare and expressed interpretations of the root causes of illness. A particular story provided some valuable insights into the relationship between stress and health and the experiences with healthcare providers:

> It is the stress that makes us unhealthy, we always have stress making those appointments, speaking and trying to get those guys in the white coats to understand and all they see is an Indian, they don’t know our language, our ways, what it is to be an Anishinaabe…

Words that reverberate and signify the pervasive lack of cultural safety inside healthcare systems are depicted through the interpretation of this statement. The resulting stress and implications for self-esteem and feelings of self worth are demonstrated in the face of a clashing system that lacks respectful understanding. Indeed a system that has vastly oppressed Indigenous people has not incorporated the genuine and respectful learning of Indigenous language and culture. The story continues:

> Our elders were taught not to be Indian to be like them or we would be punished, we were taught we are not as good as them, we deserved to be punished even though we have not done anything wrong, we only just had everything taken from us, beaten out of us, this made us sick, we couldn’t eat our food.

Powerful spoken words that attest to the loss of a lifestyle where nourishment came from the land, where the lifestyle to acquire this nourishment required tremendous fitness and where the food and water was free of contaminants and pollutants. The consequence of this devastating change would impact upon the mind and spirit and would perpetuate a deep mistrust.

> We became depressed and went to the bottle but that would kill us, many of us have no trust in the zhaagnaash [white man in Ojibwe]; many feel his medicine doesn’t work in our bodies, only Anishinaabe medicine works for us, we have had so many going to the spirit world here trying to use the zhaagnaash medicine but still we get sicker and sicker and I’ll tell you why because it is our spirit that is sick, we cannot be them, we must be who we are, the Anishinaabe, we need our language to make us better, we need our children to be learning and to speak our language in the schools, we need our ceremonies not the church ceremonies, …how can we be healthy when we don’t even know our selves, how can we feel strong?

Resounding words that passionately explicate the absence of trust underpinning the relationship with westernized medicine and the resolve to rightfully be oneself, to freely speak one’s language and be able to teach the children the ways of the people including ceremonies and culture. It becomes apparent that care and education within healthcare cannot ignore what the people are saying, how they describe the issues at hand and the way they see resolution. This is cultural safety to really listen and to hear what the person is saying, to bring back the language, the ceremonies; to restore the pride in oneself; otherwise there can be no health. For the people to have the control, the decision making power and the resources to be able to do this is central to the depiction being asserted here. In order to improve kidney health so much more must be advocated for.

4.4 Dreams

In the sharing circles the participants sometimes spoke of their dreams. Dreams have many meanings and are very important within the naming ceremony. In the community there is a naming ceremony in January. A person's name reflects their spirit and is given in the language of the people. The name may come to the elder through a dream or in other ways. Semaa means tobacco in the Ojibwe language and has a central place in the beliefs and ceremonies of the people as manifested through the ensuing story.

> In one of our ceremonies tobacco is always given first to the elder who gives the name. The name doesn't come from me it comes from the spirits…The names could come in dreams or it could be daytime or nighttime it depends on when the spirits will give the name to you. Our belief is that dreams will tell you what is going to happen…

Semaa is considered Mshkiki, a sacred medicine and is often used first to make a connection with the spirit world. Sometimes semaa is held first in the left hand; the side of one's heart, then it is passed to the right hand before it is put down to the earth. The significance of tobacco is apparent in this participant's story.

> You put that tobacco down, well you're actually meditating [and] that name will come from the spirit world, it will come in a dream and tell you, or there are many different ways of getting a name it could be through smoking a pipe, you can receive it in a sweat lodge or you can receive through another person who can

> come along and tell you a story and then oh my god you will realize their name, even just by a dream that comes, or you are walking along you can hear it or you will actually see it, sometimes you just think about it a day before [the naming ceremony]. Once they receive their name you can tell if it isn't their name, if it is the right name they are bright and they shine … I learned that along time ago.

Profound connections with the spirit world may happen through dreams. Dreams foster insights and wisdom that may guide through one's life journey. The quill box has a space for dreams within the circular and foundational birch bark walls. The dreams are always there in a person's life and may link with symbols including Indigenous art forms. Another story speaks to the significance of sacred symbols:

> The dreams might let you know what to make, you might dream of the birch bark or the sweetgrass for what you are making because they will help you know what is your journey, what you need when you walk that journey…in my dreams my body is strong, young and healthy, we believe dreams tell us what is to come…but in the spirit world I will soon be, without any pain or suffering, healthy and strong and feeling good like I am young.

Thoughts drift towards the afterlife in the participant discussions. Dreams that the participants share speak to the way health is interconnected within the deeper psyche and express the hardships and difficulties experienced. A participant shared:

> I dream of tubes and beeping noises, I dream of being free of this [dialysis], I don't want to spend the rest of my life like this…but I dream about the water because it surrounds us and it is clean and pure, then it is like my blood in my

> good dreams… I will be like this water so clean and this will be what happens when I get a kidney.

Hope transpires through dreams reflecting the hope for a kidney transplant amidst the struggles of dialysis. Water repeats itself within another participant's account of dreams.

> I lived for a while in town and always dreamt of myself trying to get back over the water to the island, I think is it my spirit going home?... see when we die we all come together, we all pay our last respects, in the traditional ways we come together with ceremonies and have the fire for four days to connect with the spirit world.

Relational ceremonies immerse the presence of the spirits. The following story expands further where the ceremonies for those who have passed are delineated.

> This helps the journey of those who have died and helps the family and relatives in their time of loss, birch bark wraps the person who has died or we make something from it [the birch bark] to scare off spirits from taking others just the one who has died, we have feasting. A medicine bundle and pipe need to be at the side of those who died for their journey to the spirit world. We come in through the east and go through the west. Sometimes the spirits will come through in dreams and whatever they ask from you, you have to give them.

From the dialogues, the expressions of ceremonies and dreams interweave within and throughout the kidney health experience, expressing the ongoing struggles, the hopes for better health, the recognition of life's phases including death and the way dreams and symbols in the materials of the quill box and birch box prevail with deep unfolding meanings.

Chapter Five Discussion

The previous chapter engaged with the living stories where meanings through the quill box methodology are circular expressing multiple connections between Indigenous Knowledge, Relationality, Cultural Safety and Equitable Access. Where ways of knowing and being are prioritized participants found strength to persevere in healthful ways in relation to their families and community. The woven sweetgrass offers a positive aroma and cleanses away the negative giving a clear vision and strength, a strength that comes from the people whose hearts are bonded together. Participants spoke of the quill box's strength in connection to the importance of family and relational being as being critical to managing and surviving with kidney disease. Anishinaabe-izhitwaawin speaks through the living stories of participants and the living stories mesh with meanings laden within the quills, the sweet grass and birch bark. Here we realize the living stories of kidney disease are expressions of the quill box methodology. The quill box interweaves expressions of Anishinaabe izhitwaawin through the living stories of kidney disease. Shining through is the harmonization of the research questions where interpretation of the living stories happens through the quill box delineation. In this synchronization, the living stories of people with kidney disease and their interpretation are inseparable – they are one.

Furthermore, the living stories emphasize how Indigenous Knowledge and relationality strengthen people and their families with kidney disease. Systemic health care structures that are disrespectful and stigmatizing towards Indigenous Knowledge stand out as a deterrent to accessibility and participation. Participants also spoke of the difficulties they encountered with health care being difficult to access as well as disrespecting and racist encounters. The health care system that is necessary for providing primary health care, dialysis and kidney transplant services is frequently inaccessible and deters participation where cultural safety is lacking.

In this manner, Chapter 5 includes a discussion that connects the findings to the interconnecting health care and educational system. The chapter is structured under the following headings: Elucidations through the Quill Box Methodology; Opening the Quill Box: Living Stories; Locating the Issues in the Canadian content including Accessibility to Dialysis, Kidney Transplantation and NHIB; Knowledge Translation including Learning from Indigenous Research for Nurses and Nurse Practitioners, Primary Health Care; Walking together; Recommendations and Final Thoughts – Conclusion.

5.1 Elucidations through the Quill Birch Box Methodology

As an Indigenous methodology, the sweet grass and porcupine quill birch box encompasses and centers Indigenous perspectives, knowledge and ways of being that have survived and are continually subjected to colonialism. Indigenous ways of being through culture, language and art as expressed by the sweet grass and porcupine birch quill box methodology flows as a unique approach to research. Eisner (1995) explains art as crafting research to foster empathetic understanding:

> [A]rtistically crafted research can inform practicing educators and scholars in ways that are both powerful and illuminating. Research with no coherent story, no vivid images, and no sense of the particular is unlikely to stick. Coherence, imagery and particularity are the fruits of artistic thinking. (p.5)

The quill box then is art and methodology at the same time. As a methodology the quill box prioritizes Indigenous knowledge, relationality and the supportive relationships between people who survive through kidney health issues through their connectedness with their ways of being and spirituality. In doing so, the methodology confronts oppressive racist schemas that have been at the root of poor health including kidney disease, poverty and social degradation. For instance the grandfather teachings of wisdom, love, respect, bravery, honesty, humility, and truth as consistent with traditional ways of being are sadly frequently lacking within today's society. Respect for Indigenous peoples is questionable in a health care system where racialized experiences have occurred and is evidenced by the low participation rates with health care and preventative services. The sweet grass and porcupine birch box has at its crux the value of respect, where all dialogues between people and nature are respected, linked and deciphered through the virtues inherent within the grandfather teachings. The birch bark in its representation of truth for example signifies a way of perceiving what truth means to a people or tribe that differs from the western construct. As Deloria Jr. (2004) shares:

> Their truths were truly theirs and others were entitled to their truths. As Black Elk saw in one vision, the universe was made up of many people, each having their own circle within which they lived. The task was to find one's own road, whether as a people or as a person, and not to worry about how other people lived their lives or what they believed and practiced. (p.9)

Interpretation as offered through the sweet grass and porcupine birch box extends the perspective that it is what matters to the people, to the person and what they themselves find as true, be it a dream or the story within the dream that therein lies the direction of one's life. The wisdom of the elders shines through the cultural teachings and traditions that mirror a healthy lifestyle through gathering food from the land in a respectful and spiritual way. Expressing values that honour the earth and living by such values requires bravery, honesty and humility in a westernized world that has frequently ignored Indigenous spiritual ways and medicines. Reclaiming ancestral traditions fosters a pride in oneself that is conducive to health. In this delineation, the sweet grass and porcupine quill birch box aims to further the cultural consciousness. Interpreting through a cultural lens as enabled by this methodology expresses the voice of those who have suffered, have experienced oppression, isolation, racism and neglect yet finds healing in Indigenous ways of being.

The sharing circles as a method of the quill box methodology involved participants holding the quill box in their hands while speaking their stories before passing the quill box to the adjacent person. This assisted in focusing the story in relation to personal, contextual knowledge and connections to the land. The materials of the quill box all come from the land and the methodology draws upon the interconnectedness to the land. Through this approach of seeing and holding the quill box the circles stimulated the sharing of the heart, where participants made comments afterwards that the circles helped to acknowledge what was felt to be important to them and from their fellow community members who also participated. In this, there was a feeling of a bonding and warmth between participants and myself where we are all going through the kidney experience together. The circles then offered the compassionate and caring means to share stories amongst one another. Lambert (2014) also explains sharing circles where everyone in the circle is equal including the facilitator where what is shared goes beyond information but also extends to emotionality and spirituality. The circles including the quill box's presence were key in bringing people together to express and reflect on the living stories in relation to kidney health.

5.2 Opening the Quill Box: Living Stories

The living stories from participants illuminated relationality and cultural knowledge as a strength amid fears and feelings of mistrust. Correspondingly inequitable access and racialized health care also emerged as root factors leading to decreased participation in health care. The participant's sharing of dreams revealed wisdom and interpretations that created living stories where dreams are not considered separate from life but immersed and enmeshed in all daily moments to guide and direct.

Fear, denial, despair are expressed through participant words in relation to kidney disease and dialysis. Time and time again though, the participants turn to their cultural ways of knowing and being that yields strength and perseverance. Positive perspectives were illuminated when speaking of the quill box in relation to being among their family, friends and community. Participants spoke to their cultural ways being the inspirational beauty and wisdom that flows from traditional ceremonies and family gatherings.

Kidney transplantation emerged through the living story of one participant, where all the feelings of fear and despair were again confronted until the new kidney offered so much hope and a chance to live life again more fully as it once was. This hope extends to the possibility of there being other human organs for transplantation and a strong confidence in modern medicine in fostering improved health. The need for modern medicine comes together with the necessity to always have traditional healing and Indigenous knowledge to heal from the obliterating blows of history. This includes the ongoing legacy and trauma from residential schools, oppressive isolation from mainstream living and widespread societal disrespect and racism. Pertinent to this discourse, is the two poles of modern medicine needed on the one hand with the same need for traditional medicines and knowledge. Similarly, “Two Eyed Seeing” recognizes the coexistence of the diverse perspectives that contribute to each other (Iwama, Marshall, Marshall & Barlett, 2009).

> Two-Eyed Seeing draws together the strengths of mainstream, or Western, and Mi'kmaq knowledges. The binocularity of this guiding principle means that by engaging the overlapping perspective of each "eye," integrative science enjoys a wider, deeper, and more generative "field of view" than might either of these perspectives in permanent isolation. It is important to note here that Two-Eyed Seeing neither merges two knowledge systems into one nor does it paste bits of Indigenous knowledge onto Western. (p.5)

The quill box methodology holds a similar distinction where the quill box as an Indigenous methodology focuses on Indigenous Knowledge and its expression through living stories and dreams. Indigenous Knowledge can support and inform work towards healthier communities. Yet at the same time it does not block out the necessity of health care. For instance the living stories that pertain to dialysis and transplant delineate the interconnectedness between ways of being, yet experiencing difficulty in accessing health care or feeling stigmatized when accessing health care. In this distinction, there is always the need to bridge the space between “cultural jurisdictions at play” (Ermine, 2004, p. 21). In the case of the necessity of dialysis or transplantation, the ongoing need for research to further understand the barriers for First Nations to accessing such vital life sustaining services is a high priority.

Participants spoke of their living stories that describe challenges in accessing services and health care that most people on the mainland take for granted. Going deeper the participants exhibited the stress and pain that comes with the constant confrontation with rejection and oppression. These are the stories of racialized experiences that Indigenous people around the world have repeatedly been exposed to and damaged by. Mistrust again reverberates through circles where medical treatments are suspect given the history of maltreatment and neglect. Bourassa, McElhaney, and Olsson (2016) address the enduring stress that inflicts great suffering and illness and leads to avoidance and low participation with westernized health care.

Considering and emphasizing cultural safety becomes an important role of the quill box methodology. Recognizing the central place of the living stories and dreams within Indigenous Knowledge and their entwinement is crucial to enacting cultural safety. Living stories and dreams in this sense are fused as the dream is part of the living story and the living story could not be without the dream. Yet the dream reveals meanings, pathways or destinies that motion the dreamer through their own living stories. This motion is like water that is fluid, seamless – makes us whole and surrounds us. Water cleanses the body not only on the outside but on the inside where the kidneys work with the water to cleanse the body and to keep the person strong and healthy both physically and mentally. Water is also critical in communities to enable dialysis and is essential to overall health.

For the quill box craft maker the healthy mind and body work in harmony, the hands gather the birch bark, the porcupine quills and the sweet grass. The birch bark comes from the birch tree that grows because of the rainfall, the porcupine quill comes from the porcupine that needs water just as the human does to grow and live and the sweet grass must also have water to grow to its adequate length to braid or smudge with. Accordingly water is spoken about in the dreams of participants, dreams that unveil perspectives of health as interrelated with the spiritual and also death and dying. Kidney health and prospects for kidney donation came into the circle of participants through the sharing of a dream where freedom from the rituals of dialysis was hoped and yearned for. Collectively the dreams shared by the participants expressed the relational attachments to each other within the community necessary for support through living with kidney disease. They also fostered learning of the importance of cultural ceremonies including death ceremonies with dreams and the significance of dreams to making meaning of health and life.

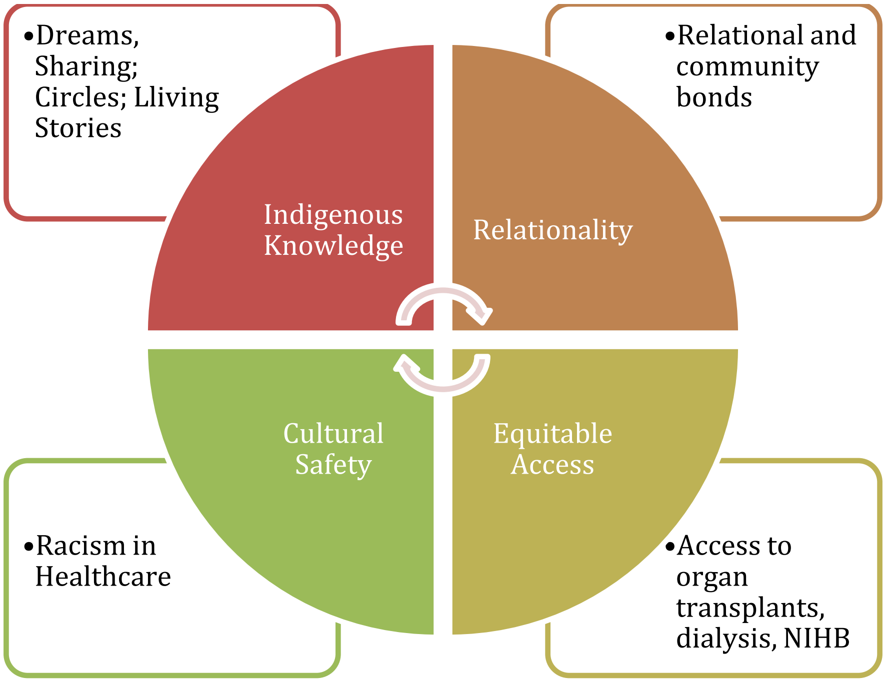


Figure 11 - Findings through the Living Stories

5.3 Locating the Issues in the Canadian Context

Accessibility to Dialysis

The interactions with and between participants often brought forth accounts of the hardships endured in accessing health services, particularly the hemodialysis clinics located off the island community. It seems logical to pursue the need for a dialysis clinic to be directly located within the community. This would be reasonable given the geographic challenges and the continual need for hemodialysis for the people residing on Chimnissing. Although there are opportunities for PD and home dialysis options, the need for hemodialysis to be available in the community supported by trained dialysis clinician continues to be necessary. This has been the ongoing case for many community members of the Beausoleil First Nation where there has been a consistent necessity for persons residing within the island community to seek medical transportation at least three times weekly to receive the lifesaving hemodialysis in the North Simcoe Muskoka. Although there have been individuals capable in facilitating dialysis within the home this is not the situation for many who have challenges with the technical equipment and the invasive procedures involved.

Currently the most accessible dialysis centres offering hemodialysis to the Chimnissing community are located at either the Penetanguishene General Hospital satellite clinic or at the Orillia Soldier's Memorial Hospital. The other dialysis facilities in the area are located at the Royal Victoria Hospital in Barrie, Ontario, Collingwood General and Marine Hospital and at Muskoka Algonquin located in Humstville, Ontario. The travel to all the dialysis centres necessitates at least a half hour ferry trip crossing the Georgian Bay Channel to Cedar Point, Ontario, approximately seven kilometers (km) to the mainland. The distance to the closest dialysis satellite facility in Penetanguishene is approximately 29.5 km to 33km. If there are not enough dialysis units available at the Penetanguishene site then the person in need of dialysis would be required to travel further to any dialysis centre with an available unit. Transportation is usually provided through the Medical Transportation program funded through NIHB. A committee member spoke to the difficulties in supporting persons needing dialysis:

> There are several here that do dialysis in town, some of them are on the same days and one goes on different days. The health centre bought a van to transport them because Health Canada will not pay a driver anymore. Our Aging at Home social worker does the driving. I think Health Canada gives $12.00 for gas per trip to Penetang. There are huge headaches every week. The winter will be worse (T. Monague, personal communication, May 17, 2017).

This situation mirrors what is happening elsewhere in the province. In Dryden, Ontario where the requirement for at least 12 persons on dialysis has been set at the minimum number before a dialysis unit would be funded. Although the number needing dialysis is less than six there are persons on PD who cannot choose hemodialysis due to the distance to the nearest dialysis centre (Marchand, 2017). PD has its challenges requiring lengthy daily time periods to complete the fluid exchanges several times a day with a potential for infection and insufficient dialysis.

This has also been the case for other First Nation communities where members are forced to live away from their communities and are not able to have their family members live with them due to inadequate funding through Non-Insured Health Benefits (NIHB) (Cram, 2016). The need for closer dialysis then becomes an issue of pragmatics amendable to health care and government funding capacity. The pragmatics include the necessity for specialized health care providers including trained nurses and technicians, clean water and sufficient power and generator services. Many First Nations are located in remote areas that lack accessibility to specialists. The communities may not have an adequate clean water supply or septic systems. The Beausoleil First Nation does have their own water treatment plant however upgrades are required to the water treatment infrastructure (Government of Canada, 2016).

In addition, the costs for dialysis treatment can range from $75,000 in an urban centre to $135,000 in a more remote setting (Troian, 2016). Higher costs are associated with the provision of kidney health services for communities that are more remote or isolated. At the same time there exists a lack of primary health services offering screening to identify and prevent further kidney damage correlated with higher rates of CKD in remote Indigenous communities (Komenda et al., 2016). “The challenge is not only to provide effective renal replacement therapy, but also to implement more effective primary prevention initiatives to delay the onset of diabetes and the progression of chronic kidney disease” (McDonald, 2014, p. 94). Lacking primary health care and screening services, higher rates of CKD and people requiring dialysis and lacking supportive services for transportation and medical therapies as provided by NIHB has mushroomed into deplorable and inequitable conditions for Indigenous people in Canada. “Conclusions regarding the reported prevalence of CKD and higher mortality rates have suggested that decreased access to specialized care for First Nations people may be a large contributor to these poor health outcomes” (Duffie & Ashton, 2011, p. 42). Despite the large amounts of research and continuance of news reports of hardships and even death as a result inadequate accessibility to dialysis and health care, NIHB and Health Canada have been largely unresponsive in making the sweeping overall changes called for (Troian, 2016).

Kidney Transplantation and NIHB

The reduced number of transplants for Indigenous people is associated with the lack of accessibility to specialist and urban centres where transplants are managed. The challenges to transplants are many including the need for the identification of a compatible donor. If a donor is not a suitable match they may be involved in the Kidney Paired Donation Program allowing the switching of kidneys to the suitable recipient. However it is not clear the degree in which First Nations participate in this program and it is likely reduced given the lesser transplantation occurring for this population. In addition, the work up towards transplantation is extensive for both the donor and recipient often at great distances. There have been complaints regarding the support by NIHB for medical transportation and the support for family members to accompany the donor or recipient in places where they may be far away from home. Contrary to this lack of financial support from NIHB that is not conducive towards First Nations persons receiving transplants is the overall cost savings compared to dialysis.

> Kidney transplants generate significant cost avoidance to the system due to the lower cost of post transplant care compared to dialysis, which is estimated at $50,000 per year per patient. With the expected 3,000 incremental kidney transplants in the proposed system, this means $976 million of cost avoidance over a 10 year period. It also means that incremental costs to the system will level off and start dropping after five years (Canada’s organ and tissue donation

> and transplantation communities in collaboration with Canadian Blood Services, 2011,p.20).

Dialysis is known to be more expensive overall in comparison to kidney transplantation. NIHB, however, appears to function with short sighted corporate goals of nonpayment for health care to First Nations so that funds can be diverted in other ways not immediately transparent. Instead the result is a costlier and sicker health care system. In 2015, the Auditor General Report, *Access to Health services for Remote First Nations Communities,* reflects the inadequacy of Health Canada and the NIHB program in providing health care to First Nation communities. "We also found that Health Canada had not implemented its objective of ensuring that First Nations individuals living in remote communities have comparable access to clinical and client care services as other provincial residents living in similar geographic regions" (Ferguson & Canada, 2015, p.23). In consideration of the overwhelming evidence, Canada has failed to provide adequate renal care to First Nation communities. Moreover, NIHB's policies prevent equitable, compassionate and humane care (Kirlew, 2016).

Through the lens of a culturally safety perspective, it becomes apparent that there is systemic racializing within the department of NIHB. Hankard (2014) describes NIHB as being driven by neoliberal policies that disregard the belief and cultural values of First Nations. Moreover, many Indigenous persons who fall within the government categories of non-status First Nations and the Metis do not even qualify to receive any support from NIHB (Allan & Smylie, 2015). There are also consistent changes to the services and medications that are covered through NIHB where many medications and services such as certain dental activities are no longer covered. Furthermore, I have witnessed many who simply give up trying to get help through NIHB leaving their health care needs unattended. This stress and frustration and the lack of adequate care resulting from such racialized programs worsen overall health and further weakens and degrades the community.

The living stories express the willingness and need for kidney transplants. The stories spoke strongly about hopes and positive experiences with kidney transplantation, the importance of family and the relational community in supporting kidney donation and transplantation. The findings further indicated barriers to kidney donation including NIHB policies that limit access to specialist services for remote communities and health care that is stigmatized and lacking understanding. This dissertation presents findings unlike those made by Davidson and Jhangri (2014) that generalize Indigenous people as non-accepting of organ donation due to cultural perspectives. The concern is that this presumption may lead to health care providers not actively engaging earnestly in communicating with Indigenous people regarding organ donation.

Ermine (2004) depicts the many issues that may result with a “pathologizing lens” resulting in “skewed representations” that dehumanize and paints all Indigenous people with the same brush thereby perpetuating stereotypes (Ermine, 2004, p.12-13). The history of research within First Nation communities has often taken the approach of power over where stereotypical assumptions generalized Indigenous people (Snow et al, 2015; Smith, 2012).

On the otherhand, Dr. Misty Wilkie-Condiff ‘s 2009 dissertation, *The Lived Experience of American Indians and the Organ Donation and Transplantation Process,* highlights the barriers to organ donation that include wait times and accessibility. The study informs of the encouragement to become donors within the Indigenous community (Condiff, 2009). Likewise, another American study completed in 2013 by Jernigan et al. (2013) describes changing viewpoints towards organ donation. “Most participants were supportive of organ donation and willing to donate to a family member, concurring that traditional beliefs have their place, but may not be relevant to this issue” (Jernigan et al. 2013, p.8).

As depicted throughout this work, methodologies that originate from the contextual and cultural knowledge of the community are less likely to submit stereotyped and potentially harmful research that continues to denigrate First Nation people.

> Historically and presently, the majority of health research conducted with Indigenous populations has been and is led by individuals of non-Indigenous backgrounds. This ultimately raises ethical concerns regarding the orientation, conduct and implications of research from differing health knowledge systems. Western or non-Indigenous-based research and Indigenous knowledge systems may have polarized orientations, and this has ignited debate about which system is the appropriate authority for describing Indigenous health knowledge through research (Kolewaski & Yeates, 2009, p. 572).

In recognition of the debate as depicted by Kolewaski and Yeates (2009), research has come forward in advocating for participatory action research (PAR) to engage populations that may garner insight into the social inequities involved in the growing issue of kidney disease and care. Yet PAR has also been criticized as granting approval to Indigenous people to participate in another form of a Westernized based methodology that lacks full immersion with Indigenous ways of knowing and being (Zavala, 2013). As well community based participatory research was not founded upon Indigenous or tribal knowledge, relationality and its extension to the relationship with the land (Kovach, 2010; Alcantara, Lalonde & Wilson, 2017). The quill box methodology prioritizes relationality, the supportive relationships between people who survive through kidney health issues through their connectedness with their ways of being and spirituality. In addition the quill box methodology involved community consultation and participant feedback of transcripts and analysis. In this respect, the quill box is an Indigenous methodology that shares many features with PAR. Particularly the methodology shines in its decolonizing potential that targets societal structures that unfairly negates the decision making power in determining health.

5.4 Knowledge Translation

A discussion concerning knowledge translation begins this section that further includes the significance for Nurses and Nurse Practitioners, Primary Health and Recommendations. The consideration extends knowledge translation (KT) of the findings in relation to health care education and care. Then the central ideas of the findings imbue the recommendations.

As a starting point, this discussion will consider the quill box methodology in relation to the academy's HREB, the OCAP principles and (KT). Estey, Smylie and Macaulay (2009) provide a useful document that contrasts the definition of KT within Indigenous contexts from that of the Canadian Institutes of Health Research (CIHR). One definition that has been used to describe KT in Aboriginal contexts is: sharing what we know about living a good life. This is quite different from the Canadian Institutes of Health Research (CIHR), which defines KT as: a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system. (Estey, Smylie & Macaulay, 2009, p.3)

As Indigenous communities are diverse in many ways, the consensus from many prominent authors is directed towards research and KT that specifically empowers and furthers the specific community's needs where the research is proceeding (Kaplan-Myth & Smylie, 2006; Wilson, 2008). Indeed, KT has always been occurring within and between Indigenous communities where the knowledge to live in harmony with the land had enabled survival throughout history. In this perspective, knowing and doing cannot be separated and are always tied to the overall benefit of the community (Morton Ninomiya et al., 2017). On the other hand, the CIHR broadly speaks to KT as benefitting the health of all Canadians, "to yield beneficial outcomes for society" (CIHR, 2006, p.6).

KT is most often "based on the premise that knowledge is acquired through 'evidence-based' research" that has been critiqued as being inappropriate within health research concerning Indigenous contexts (Morton Ninomiya et al., 2017, p.2). Estey, Smylie and Macaulay (2009) also explain that:

> [C]ontinuing to apply Western science-based evidence perspectives will only further marginalize Aboriginal ways of knowing and perpetuate Aboriginal/non-Aboriginal inequities. This is particularly the case for Aboriginal health interventions, which are complex both in terms of the intervention and the community context and are not easily evaluated by the standard RCTs. (p. 4)

Moreover, the terms "wise practices" is suggested rather than "best and evidence-based practices" (Morton Ninomiya et al., 2017, p.3). This perspective of KT and the diverse unique Indigenous community versus the larger Canadian context is significant to the quill box methodology that arises through this dissertation work. As the methodology derives from the author's perspectives in tandem with the unique perspectives of the community and cultural knowledge practices, KT aligns with the underpinning values of the community that are consistent with the Anishinaabe Seven Grandfather teachings. The teachings represent the values that form the ethical structure of the methodology. The teachings of respect also relates to ownership, control, access and possession as specified by the OCAP principles.

> The term 'respect' is consistently used by indigenous peoples to underscore the significance of our relationships and humanity. Through respect the place of everyone and everything in the universe is kept in balance and harmony. Respect is a reciprocal, shared, constantly interchanging principle which is expressed through all aspects of social conduct…The denial by the West of humanity to indigenous peoples, the denial of citizenship and human rights, the denial of the right to self determination – all these demonstrate palpably the enormous lack of respect which has marked the relations of indigenous and non-indigenous peoples. (Smith, 2012, p. 125)

As the traditional knowledge emerges from the community, it is their knowledge, possessed by the community, accessible to the community, yet it may be shared in a respectful way that benefits the community. Indeed knowledge may be considered critical to the goal of self-determination. In renal health care self-determination may involve the provision of dialysis where First Nation communities would have their own accessible dialysis centres managed through Chief and Council and Band Health Services. In this perspective knowledge from research directly empowers the governing and decision making capacity within the community and supports the required infrastructural expansion necessary. This also links with the concept of knowledge holders as described in section 3.7, where the community will seek its members to provide contributions that they are particularly knowledgeable about. In my situation, this was related to my involvement as a kidney donor, my history as a community nurse and nurse practitioner and community member. "When locating ourselves within the research, it is also important to recognize that personal growth is an important end product" (Lavallée, 2009, p.26). In this perspective, the knowledge that I as the researcher held at the outset was important to the community, however, this knowledge has also increased exponentially whilst undertaking this initiative.

From another angle, the traditional ways of knowing and cultural symbols may be distinguished in terms of cultural autonomy. In cultural autonomy, those of a culture assert their symbols, language traditions. This is in contrast to the appropriation of Indigenous Knowledge to gain something by those outside of the community or essentialism where all Indigenous knowledge is categorized as being essentially the same (Matthes, 2016). Inherent to the quill box methodology is the community context and knowledge that is prioritized beyond mainstream westernized methodologies. Respect is prioritized when the community's ways of being and knowing guide the methodology and methods. The methodology that arises from the community towards actions and activities that benefit the people is consistent with self-determination.

In analyzing the living stories it was also important not to dissect and segment stories as is common to qualitative analysis of interviews or focus groups (Lavallée, 2009). Simonds and Christopher in 2013 explain that the Crow people interviewed in their study revealed that they found it disrespectful to break apart the sacred stories from elders and not to mention names of those from who the stories came from. Lavallée (2009) also expresses “it became evident that this ‘standardized’ way of analyzing qualitative data was problematic for this Indigenous approach because it seemed to tear apart the stories of the participants” (p. 34). The quill box methodology prioritizes the living stories and the circle where the stories followed each other where they often began with the elder in the circle. In addition, to the process described in section 3.6, the participants were informed from the outset that their stories would also contribute to their expression of their experiences towards the purpose of improving awareness and creating positive action within the community. Also the living stories are relevant to services outside the community such as the dialysis centres that have implications for kidney health care for the community. Approaching the living stories from this direction aligns with the principles of respect where the analysis, management and implementation of the living stories was in harmony with the information shared through the outset of the proposal development, community’s consultation meetings and consent forms.

The quill box methodology steers away from emulating other mainstream methodologies. Furthermore, the quill box methodology emphasizes the transformative perspective that methodologies that arrive from other than Westernized origins may be developed by, for and with the community to maximize the success that the research will benefit the community. Inadvertently this very process increases knowledge that may be transmittable to furthering new methodologies that disrupt entrenched patterns. This way of thinking has the potential to open the door to ‘outside the box’ strategies that risk going beyond the westernized norm to bring in the voices of those who have long been oppressed yet may create lasting significant positive change within their own back yards. Focusing on the contextualized Indigenous Knowledge to guide the methodology approach decolonizes and epitomizes the community’s relational strengths and traditional values.

The quill box is a form of art that represents both doing as in craft making and Indigenous Knowledge that radiates from the special community circumstances. Such special circumstances involve that the community population is centered on an island in a geographically remote area, is dependent upon ferry services that is likewise dependent on the Georgian Bay channel conditions and weather. These conditions also have implications on the degree of access to mainland health care specialists and hospitals. Additionally the remote island circumstances have allowed some preservation of the Anishinaabe cultural knowledge, language and ceremonial practices that have also contributed to its distinctiveness and individuality

Learning from Indigenous Research for Nurses and Nurse Practitioners

Participants in the sharing circle spoke of their interactions within health care. Words conveyed the lack of respect felt and the stigmatized views of degradation. Nurses and Nurse Practitioners are required to provide ethical and cultural safe care, yet the participants’ language did not always communicate that this happens. Given this need for cultural safety, it helpful to consider how Nurses and Nurse Practitioners may engage in further education as well as research. In addition it is relevant to explain this aspect of KT for Nurse Practitioners that have historically provided care to remote and isolated communities.

The research as provided in this dissertation offers a rare perspective of a Nurse Practitioner (NP) involved in research within a remote First Nation community when there is otherwise a dearth of research activities amongst First Nation groups that involves NPs or nurses in general. In light of the growth of the provision of primary health care by Nurse Practitioners in Canada it becomes relevant to this discussion to consider the potential for NPs to further engage within research initiatives involving First Nations. The Canadian Nurses Association (CNA) correspondingly explains that remote communities are experiencing an extremely dire shortage of health care workers, in the fact sheet, "Nurse Practitioners in Rural and Remote Communities" (CNA, 2017). Nurse Practitioners have their origins rooted in remote outpost communities and the majority of NPs in Canada are primarily educated within the Primary Health Care or Family/All Ages programs. Despite this there remains a lack of NPs working in multidisciplinary teams and in remote or rural communities (CNA, 2017; MacLeod, et. al, 2017). The proportion of the NP workforce located in remote communities impacts on the likelihood of NPs becoming involved in research initiatives when there are limited NPs involved in remote settings. In addition, NPs have also indicated reduced protected time for involvement in research or scholarly projects (Mian, Koren & Lacarte, 2012). In this regard, there is potential to build upon the learning that may enable the research potential of NPs and nurses to be involved in research activities amongst First Nations (FN). Research that creates awareness of health and its associated sociopolitical cultural context is necessary to determine effective strategies that strive towards improved outcomes.

As a Primary Health Care Nurse Practitioner in Ontario, I have a unique opportunity to contemplate the learning for NPs as relevant to the primary health care focus. In September 2017, the presentation entitled, "Learning from research within a First Nations community: A Nurse Practitioner's Experience", was provided at the Nurse Practitioners Association of Ontario conference in Toronto, Ontario. The objectives included to further the potential for NPs to engage in research with FN communities, to develop innovative research methodologies that are consistent with FN ways of being and knowing and to foster active participation conducive to improved health outcomes through a NP research initiative. The audience was asked first of all why should NPs do research and why should NPs do research within First Nation communities? Audience participants brought forward the idea that research may help to guide NPs in providing optimal care and how this care may differ from what is generally provided for non - First Nation populations. The emphasis for NP research was also reinforced through the depiction of the need for primary health care in relation to the lack of such care and the implications for chronic disease management within remote communities. In addition, reference was made to the new Entry Level Competencies for NPs that were devised by the Canadian Council of Registered Nurse Regulators (CCRNR) in 2016. The new competencies that are consistent throughout Canada may serve to not only enhance the labour mobility of NPs but includes competencies that promote research. The competencies also emphasize culture safety in client care. Specifically the words "participate in research" and "relational strategies" and "culturally safe care" have resonance (College of Nurses of Ontario, 2016, p.4 & 6). In this approach, the competencies link with the Truth and Reconciliation Commission of Canada's Calls to Action that direct education towards confronting the perpetuating colonial realities shaped by the historical events of the past. The competencies provide the structure to support NPs in the provision of culturally safe care and to be involved in research. Together the competencies and the CNA's description of the need for "innovation and initiative" relate strongly with this dissertation (CNA, 2017). The quill box methodology promotes learning of Indigenous Knowledge and culturally safe practice to further understand a chronic disease, i.e. CKD and ESRD. As a community driven methodology, participation and engagement by the community was prioritized. The wisdom acquired through the actual experiences within the community in combination with the knowledge gained through associated literature culminated in learning that is to be shared amongst the nursing world. For instance, the importance of being reflexive and to answer the question of who you are in relation to the community was spotlighted as enabling reflections upon one's assumptions. Looking at ingrained taken for granted assumptions fosters introspection of colonialist or racialized entrenched patterns that impact on relationships with community members (Baez, 2011). As depicted by Rix, Barclay and Wilson (2014) journaling offers a method to evoking self-reflexivity where the intent is to identify previously unrecognized ways of being that demean the other. Reflexivity bridges the in-between space. Reflecting actively or critical immersion involves deliberating and exploring one's own experiences of culture to appreciate difference, privilege and power hierarchies (Snow et al., 2016, p.10).

Through self-reflection, I felt it important to think towards my position in leading this study. As I was engaged with participants who are well known to me within the relational context, I felt awkward at times knowing my position as researcher given the way history has caused mistrust towards research. Ermine (2014) describes this situation where Indigenous researchers are fearful of using the word research instead using terms such as project given the distress caused by colonial investigations of the past.

In addition, although I was aware of the hierarchal structures within government and political systems I would come to appreciate at a far greater level how difficult it is to further awareness to action. For example, I had the privilege to attend the Parliamentary Health Caucus in June 2017 where I was able to meet with several very influential politicians and Indigenous health advocates and researchers. In a discussion with one particular politician, I was explaining my research endeavors where the discussion revolved around the cause of kidney disease. Diabetes was spoken about where the politician emphasized diabetes as a preventable disease. I then asked this politician what she thought was the cause of this epidemic of diabetes. I could then feel the tension as I experienced her statement regarding preventable causes as a continuance of the "blaming the victim mentality" where lifestyle is overwhelmingly depicted as the cause of ill health. I spoke of the implications of colonial history of oppression, poverty and loss of ways of being that supported healthy lifestyles where our brief meeting and discussion ended shortly after. Fully on my mind at the point was this incredulous situation where the majority of political leaders are non-Indigenous having been educated within a system largely devoid of the learning of the history of residential schools, assimilation and colonization. Research that unveils the perceptions from Indigenous people themselves regarding the implications of stereotyping and pathologizing assumptions that further perpetuate impoverished and inequitable situations that are harmful to both the physical and psychological well being should be informing politicians and policy makers towards equitable and ethical action. Indeed, nurses, Indigenous nurses and nursing organizations need to be engaged in the decision-making processes as stakeholders to shape policy, regulations and laws that foster Indigenous representation in education, healthcare and governance if the Truth and Reconciliation's Calls to Action are to be realized.

During the recent presentation at the Ontario NP conference, an audience member asked how I felt regarding non-Indigenous nurse researchers conducting research in First Nation communities. Knowing how critical self-reflection, introspection and immersion may foster relationships having genuinely disrupted ingrained assumptions, it becomes sensible to consider non-Indigenous researchers and their capacity with First Nation communities (Snow et al. 2016). The researcher as a person may not necessarily be an insider or an outsider yet they may be somewhere between these two poles (Kerstetter, 2012; Kusow, 2003, Summers, 2013). Positioning may also then depend on individual characteristics and the group a person chooses to identify with. Of importance though, is the trust that is established through a person's disclosure of their identity and the way they relate to all who may be involved in the research (Innes, 2009). Indeed this relating ties together with the relational value that further develops trust and a respectful connection that moves towards positive outcomes. It also fosters cultural humility where the person doing the research acknowledges their own way of being and who they are in relation to community members with distinct ways of knowing and being. Moreover, reflexivity may encompass the genuine attention to the community's history and emotions in response to their historical experience. This cannot be understated. Researchers in First Nation communities are needed and their ongoing involvement with the community upon the completion of the research sustains the well-intentioned relationship. From this outlook, nurses may come to realize their potential to become involved in research with First Nations that serves to benefit the community.

Primary Health Care

As we consider the goals of primary health care, focused on prevention and education, the prevalence of kidney disease within First Nation communities is largely attributed to diabetes (Ashton & Duffie, 2011). Frequently the approach taken by health care providers is to fixate on screening and target lifestyle choices that lead to obesity. This may be effective only to a certain point. Reading (2015) makes the important point:

> If we hope to appropriately address diabetes, we must first understand what determinants are influencing the development and persistence of this debilitating and life-threatening illness. Yet, if we limit our analysis to its proximal determinants, as is often the case, we will continue to focus our attention on obesity, poor diet, and sedentary lifestyle… If we search deeper still for the determinants responsible for shaping these conditions, we discover the root of the problem — a colonial structure—fashioned from the centralization of Aboriginal peoples into remote communities and reserves, the oppressive nature of the Indian Act, the damaging legacy of residential schools… (p.11).

It becomes apparent that health promotion has limitations. Dr. Barry Lavallee explains "[w]e have to try to stop framing health promotion from a middle-class view. The problem is not fruits and vegetables. The problem is that people in the north can't hunt because of the pollution caused by destruction and pollutants…mining, forestry, and hydro" (Mitchinson, McPhail & Ellison, p.183). It may have been easier to focus on the fruits and vegetables, yet without digging for the root of the problem or "colonial based racism" there can be no meaningful improvements to health and this includes kidney disease (Diffey & Lavallee, 2014).

5.5 Walking Together

It is necessary to address potential plans to rectify some of the concerns in light of the discussions regarding the daunting issues facing the community in terms of accessibility for dialysis and kidney transplant. First, the issues require multi level changes throughout the system and this calls for consensus by all parties and stakeholders. Furthermore, there needs to be an understanding and recognition of the intricacies of the issues that are best conveyed through the participant living stories that convey the hardships endured as well as ideas for improvement. From the living stories it becomes clearer that primary health care that offers kidney screening and prevention of ESRD must be delivered in a manner that is culturally safe and fully engages the participation of the community. This also beckons the need for community members to become the health care providers themselves as well as engaging in the ongoing educational interactions that develop culturally safe health programs. The participants also conveyed that they want the emotional support and learning that comes from directly speaking with others who are going through similar circumstances. This need aligns with expanding the potential of already existing services such as the Kidney Foundation of Canada's Peer support program within an Indigenous framework that involves and engages Indigenous spokes-persons and community members. As well building capacity to further support First Nations communities through such entities as the Ontario Renal Network as operationalized through Cancer Care Ontario and the Ministry of Health and Long Term Care would require consistent and sustainable support to create cultural safe strategies with action plans and outcomes. Furthermore, the development of the community infrastructure to enable accessibility to specialist services or community accessible dialysis and transplant care requires an overhaul of Health Canada's NIHB program and the direct involvement of overarching governing systems. The governing systems need to work closely and listen responsively to the community Chief and Council. This would enable a respectful exchange that learns from the living stories and works united to advance impactful change to lessen the burden of renal disease. Actions in this regard are consistent with Recommendation 19 of the 2015 Truth and Reconciliation Commission of Canada, Calls to Action.

> We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services (Truth and Reconciliation Commission of Canada, 2015).

Chronic diseases include renal health, CKD and ESRD. The meaning of this recommendation may be extended to the goals of providing sufficient funding to provide safe and reliable transportation across the Georgian Bay channel from Cedar Point to Christian Island, increasing health care services directly to the community including specialist, medical, nursing and nurse practitioner services in conjunction with expanding traditional healing services. Creating a designated dialysis centre directly within the Chimnissing island community that would offer at the same time an active kidney screening and prevention program and a strategy to streamline ESRD persons for kidney transplantation is a high priority. Another option is to provide intensive support for home dialysis options that would aggressively seek to overcome any barriers. An example would be someone to assist with self-cannulation for those who have difficulty with the procedure. To support dialysis in the community, the funds to develop the health, water and septic systems is necessary and this again compels a functional relationship between Chief and Council and government that activates timely and appropriate revenues.

This analysis supports the research that presents the statistics and extent of issues concerning Indigenous kidney health that stands out in the literature review. Yet there is a lack of research that distinguishes kidney health utilizing an Indigenous methodology where cultural safety is prioritized. One of the few studies that link with this endeavor in that it yielded insightful stories from participants was conducted by the Canadian Council for Donation and Transplantation (CCDT) in 2005. This study relates the need to extend the dialogue, to include elders, language interpreters, community circles and Indigenous educational materials. The challenges to dialysis in remote conditions and racialized experiences are also highlighted. As the findings align with the living stories from the quill box methodology, the issues as previously discussed facing First Nations become more transparent. Knowing the issues is critical to strategizing actions towards improved care. This is of high relevance to health care providers, policy makers and research initiatives.

In June 2017, I had a unique opportunity to meet with Indigenous scholars and political leaders at the Parliamentary Research Forum in Ottawa, Ontario. This turned out to be an occasion to make heartfelt connections with all those involved to discuss the many personal experiences I have with kidney disease as a community member within a First Nation community and also from the perspective of a Nurse Practitioner. Through representations of the quill box methodology, methods and particular messages from the living stories, I was able to be with people like myself who have genuine intentions to improve our lives but also to learn and expand and contribute to knowledge (See Appendix B). This served to be knowledge translation, whereby walking with others means listening openly and being receptive to perspectives that break down barriers. Walking together is building the relationship and coming together to make new connections and discover fresh meanings.

5.6 Recommendations

Given the previous discussions and the participant living stories in chapter four, the recommendations need to pertain to the areas Indigenous Knowledge, Relationality, Cultural Safety and Equitable Access. The recommendations overlap as Indigenous Knowledge and respect for Indigenous Knowledge is necessary for all the recommendations.

For Indigenous Knowledge, it would be an important recommendation for health care providers, health care educators and students to be genuinely engaged in education as per the Calls to Action made by the Truth and Reconciliation Commission of Canada.

Education should involve elders and engagement in community protocols that emphasize the value of respect. In addition, all activities that promote Indigenous Knowledge within the community should be included. This may extend to language programs, community activities including pow wows, sweat lodges, community feasts and traditional healers. There are likely many creative opportunities that may further Indigenous Knowledge within elementary and high schools. This may extend to the development of resources on kidney disease from an Indigenous perspective where traditional ways and foods may be encouraged. Furthermore, a committee that meets regularly may involve elders, knowledge holders and community members who engage and strategize with involved health care workers. This group of dedicated people would strive towards community driven programs that instill traditional protocols and practices.

Indigenous methodologies including the quill box methodology are built upon distinct Indigenous Knowledge systems and contextual protocols. They have riveting significance for the academy and will require intensive learning that may unsettle and challenge established westernized research methodologies. The potential to develop research methodologies within the contextual community is possible and is exemplified throughout this work and through a growing number of Indigenous scholars. Representation of the Indigenous community and elders within the academic setting is critical, as well as for all faculty to recognize their responsibility to learn and engage within Indigenous ways of knowing and being. Another associated recommendation is that students serious about using or developing a methodology receive increased support. Indigenous methodologies have great potential to improve and identify ways to further health care and education. However, learning Indigenous methodologies includes the necessity to opening up to a history that lies at the root of many health issues, a history that may stir up trauma and distress. Students should be genuinely supported through stressful or contentious circumstances in light of their potential to contribute to their communities.

In relationality, the previously mentioned community activities also support the coming together to share hearts and minds to strengthen relational bonds. Relationality is also influenced by legacy of the Indian Act that has divided families further. Changing the Indian Act involves a political movement and the broader governing systems within communities. Healthcare for families with kidney health problems may make provisions for larger families to visit within health care institutions, while receiving dialysis or when ill. Furthermore, areas in facilities providing health care should include areas where smudging or visiting families to unite. Peer support and support groups are vital given the trajectory of dialysis, fears of rejection with kidney transplant and the life changes that occur with kidney failure.

With regards to cultural safety a recommendation would be to increase the representation of Indigenous faculty, students and health care providers. This would also help to bring Indigenous Knowledge within the academy and health care setting. As previously described, education needs to target culturally safe practices where stigmatization and racist experiences are brought to the fore to learn from them. The need for a community committee and support group may offer an approach for people to come together to identify their experiences with health care.

Accessibility recommendations include furthering access to services such as dialysis to be provided close to home, in the home or within the community. Also access to specialized nephrologist services for kidney transplant work ups and developing Internet or web based technologies to enable specialist services from a distance. Screening services should be available within the community that involves the community in screening to further participation and acceptability.

5.7 Final Thoughts - Conclusion

Realizing sustainable actions that address and work toward improving kidney health for First Nations demands building a relationship as informed by the Call to Actions as set forth by the Truth and Reconciliation Commission of Canada (2015) and that abides by the United Nation Declaration on the Rights of Indigenous Peoples (UNDRIP). This relationship occurs between community Chief and Council and political stakeholders where the living stories flow through an Indigenous methodology like the quill box methodology. The living stories emerged to delineate existing circumstances and suggest potential ways to effect positive change. The pervasiveness of colonization continues to adversely impact upon the health and wellbeing of First Nations communities where historical trauma, oppression and the loss of a once healthy way of living have all come together to create the poor health conditions including CKD and ESRD. As spoken to within the Truth and Reconciliation Commission 2015 report, it has taken many years to create the present situation and will likely take a very long time to make improvements. Respecting and bringing back the traditions and ways of the people and embodying Indigenous Knowledge through research, education and in health care are reflected throughout the Calls to Action and aligns with self-determination right of UNDRIP (UN General Assembly, 2007).

This may be a turning point in history where both the Truth and Reconciliation Commission of Canada and UNDRIP have put at the highest priority the relationship between Canada and First Nation people and communities. From this standpoint, there is impetus to bring great change and decolonize the very policies and societal structures that continue to obstruct equitable circumstances for First Nation communities. This all translates into improved, accessible and culturally safe care for all my relations with kidney disease. First Nation people who have decision making power will choose a healthier life for themselves where they control health services, medical transportation etc. With adequate funding and partnership with kidney specialized services, the planning may begin where the living stories reveal the collective dreams of health and vibrancy.

Coming to know the living stories through the quill box methodology offered a means to illuminate the perspective from a cultural context that strove away from common Westernized methodologies. In this challenging endeavor, great learning happened with regards to Indigenous Knowledge, Indigenous Research Methodologies and the ethical implications involved. All of this is happening within a time where First Nation people are emerging from the oppressed colonial history and intergenerational traumas to take a stand today. This has been demonstrated through the Idle No More movement and Reconciliation events throughout the country. Amidst all of this there are those who are suffering or just finding out that they have CKD. As well there are those who are on dialysis or waiting for a kidney transplant. Many are living in remote areas lacking access to the necessary health care services to sustain life. Frequently the living stories delineated access issues in conjunction with health care that stigmatized and led to decreased participation and engagement with mainstream health services. In this distinction as set forth through the living stories as presented in this dissertation, it becomes clear that challenges to overcome are great yet it is through understanding such challenges as afforded through the living stories where the action may begin.

The quill box methodology provided a way to learn the living stories and this methodology offers great potential in growing as an innovative culturally safe Indigenous Methodology. As a new conception, the quill box methodology is not perfect and subject to change as the contextual circumstances of the community flux over time. Indeed, it would also have been extremely interesting to have involved adjacent communities in this study that would offer the opportunity to determine similarities and differences in perspectives associated with the kidney health care. This may be a possibility for future initiatives that would welcome adequate funding. Within an Indigenous paradigm, the quill box methodology does not divide the supernatural from reality or assert truths and thereby measures rigor in terms of authenticity and trustworthiness. As in the making of the quill box, gathering the sweetgrass, birch bark and quills and crafting them into a form of art, the materials of the quill box reflect Anishnaabe-izhitwaawin and thereby links with Indigenous Knowledge, relationality and history. The craft making into art is akin to the methodology where the materials from mother earth enmesh with the ceremonies and knowledge that flow into living stories. In turn the living stories reflect ways of being and knowing essential to spiritual and physical well-being.

The sharing circles offered support for community members with kidney health issues and it was made clear by the participants and other community members including the Chief and Council that they would like this support to continue. As a result, the

‘Kidney Circle’ is evolving into a peer support group and network involving the Kidney Foundation of Canada’s peer support program. Several participants and community committee members have come forward explaining that they would also be interested in offering peer support to fellow community members experiencing kidney health issues. In light of the community interest, Nookmis has also included support to sustain the circle for this year. So as a circle has no beginning or end the Kidney Circle continues to support and guide further actions for improvement and change within the context of this First Nation’s community. As per the OCAP principles of ownership, control, access and possession, this dissertation will be readily available to the community and Chief and Council for their ownership as described in section 3.5. It is through their control and possession of this work that they may choose to further embark on accessing the data in supporting further initiatives such as the high priority issues of accessibility to dialysis and kidney health services. Nevertheless, as a community member I am committed in this regard to the lifelong relationship to improving kidney health for the community.

Since the first community consultations that occurred in 2016, the community has been actively involved in facilitating kidney circles or support groups. In addition, there has been several community meetings involving governing community representatives and mainland community kidney services to come together and hear the stories from the community about their experiences in accessing dialysis and obtaining kidney transplants. Stories are leading to making changes where stakeholders are working together to further modalities including home hemodialysis and peritoneal dialysis. The community continues to strive towards preventing kidney disease and assisting transportation to and from dialysis as well as supporting kidney and organ donation.

Through this dissertation and final stage of my PhD journey, it may be discerned that kidney health care is a very high priority in First Nation communities. Although the research took place in only one First Nation community, it may be realized that together through the literature and other research as brought forth in this paper, that First Nation communities across Canada are experiencing many of the same issues with regards to CKD and ESRD. The need for culturally safe health care services and improved accessibility to primary health care, dialysis and kidney transplant care is of paramount importance where all First Nation communities and all of our relations share the dream of a strong healthy mind, body and spirit. Listening and learning from the living stories as made possible through this dissertation and the quill box methodology may be considered to be a meaningful contribution towards furthering kidney health care.

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Appendix A- Participant Consent Form

The Living Stories of Chronic Kidney Disease for First Nation People

You are invited to participate in a study entitled, The Living Stories of Chronic Kidney Disease for First Nation People that is being conducted by Mary Smith, Nurse Practitioner. This research is being undertaken for the PhD program in the School of Nursing at the University of Victoria. Dr. Carol McDonald is Mary Smith's Supervisor at the University of Victoria and you may contact her at (250) 472-5280 or carolmcd@uvic.ca if you have any questions or concerns about this study.

Mary Smith is a PhD(c) in the School of Nursing at the University of Victoria and you may contact her if you have further questions by phone at 705-549-3504 or email at msmithnp@uvic.ca. Mary Smith is a member of a First Nation community and has experiences with kidney disease within her family and is a kidney donor.

Purpose and Objectives

The purpose of this research project is to learn more about experiences as a First Nation person with Chronic Kidney Disease (CKD). The objective is to bring forward experiences and the way a person views and understands their kidney disease so that problems or issues can be identified as well as factors that have been helpful.

Importance of this Research

Research of this type is important because it may help to better clarify the difficulties or hardships experienced as well as possible ways that things can be improved.

Participants Selection

You are being asked to participate in this study because you are a member of a First Nations and have volunteered to participate **and that you are also an adult living with chronic kidney disease.**

What is involved?

If you agree to voluntarily participate in this research, your participation will include participating in 3 sharing circles (a group of people who also have kidney disease and are First Nations) with Mary Smith. The sharing circles may occur for **2-3 hour durations** at a time for a total of 6 hours in sharing circles occurring on different dates. **Each person is the circle will have their own time to speak. A talking stick will be passed around the circle that designates the speaker who is holding the stick. This will allow the audio taping to capture each participant's contribution.** After each sharing circle each participant will be given $20.00 to cover the cost of transportation. Mary Smith will be recording the sessions with a tape recorder. All tape recordings are confidential and kept under lock and key. The taped recordings will be listened to carefully by Mary Smith who will type it out and identify what the main points are. As the recordings include the dialogues of the participants, the recordings cannot be returned to individual participants. The typed text is called a transcription and the main points are the themes. The themes are statements that best explain the situation or the problem. The same will occur for other participants. Together the themes from all the participants will help to describe the experience of living with kidney disease and what the problems are. Knowing the problems can be a first step to exploring solutions. The location will either be in the local health centre or public building / community facility where a private area without interruptions can allow the sharing circles. Mary Smith will write a report of the transcription and you will be asked to verify that what is written describes the meaning that was intended.

Inconvenience

Participation in this study is not expected to cause any inconvenience to you, except for the time required to participate.

Risks It is possible that health matters or mental health issues may arise that necessitate health care. Should these situations occur you will be assisted to the appropriate care such as physicians, paramedics, mental health services, traditional healers etc). **Frequent breaks and healthy beverages and snacks will be offered to participants who may experience fatigue.**

Benefits

The potential benefits of your participation in this research includes the identification of problems or issues or what is helpful in the experience of kidney disease. This may help to determine ways to improve situations that are common to people who experience kidney disease.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be used only if you give permission through signing a consent form otherwise the data will be destroyed.

Participants will be able to leave the research without this decision impacting their personal relationships and possibly their health care relationships with Mary Smith.

On-going Consent

By signing this consent form you will giving consent to participation in the sharing circles and the process of reviewing the transcripts (the typed text) to assure accuracy. **Continued consent is conveyed by attending each sharing circle.**

Anonymity

In terms of protecting your anonymity, data will be identified by a participant number; your name will not be used in either analysis or dissemination of results. However, your identity will be known to Mary Smith during data collection and analysis and to the other participants in the sharing circle.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected by password on the computer used solely for this research and is kept locked in a cabinet that is further locked in an office. Participants in the circle will be asked not to share data in a way that connects it to particular participants in the circle. **Sharing experiences and information in a group setting means that the researcher cannot guarantee that the experiences and information conveyed will not be shared outside the group.**

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the form of a report and to communities involved.

Disposal of Data

Data from this study will be stored in a locked cabinet with a locked office and disposed of by deleting electronic data, paper copies will shredded. **The research may be shared through Mary Smith's PhD dissertation, publications and conferences.**

Contacts

Individuals that may be contacted regarding this study include Mary Smith, by phone at or email at msmithnp@uvic.ca. or Carol McDonald by phone or email at carolmcd@uvic.ca. Contact information is available at the beginning of this form.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers. *[Signatures here] A copy of this consent will be left with you, and a copy will be taken by the researcher.*

Appendix B-Recap for Parliamentary Forum
From the Proposal Dissertation: The Living Stories of Chronic Kidney Disease for First Nations People

by Mary Smith, PhD(c) in Nursing – University of Victoria (UVic), msmithnp@uvic.ca

Aims

- Further the cultural consciousness
- Reclaim ancestral traditions and good health
- Express the voices of those who have suffered through colonialism
- Identify and address systemic barriers
- Increase knowledge that furthers cultural safety

Background and Context – The study sought to further engage with the living stories of Chronic Kidney Disease (CKD) in a First Nation community. Participants involved the Beausoleil First Nation who are mainly of Ojibwe and Potawatomi origin. The community and supervisory committee supported the proposal that was also granted UVic ethics approval. Mary Smith is a Nurse Practitioner, a community member and kidney donor with relations with CKD. Through living stories the contextual and cultural expressions of CKD are voiced. Listening to the voices centers culturally safety that acknowledges the historical issues of oppression and colonization and prioritizes Indigenous knowledge. Critical for health care providers and ethical health care is to listen to the voices through living stories. The need for research that seeks to discover the living stories of First Nations peoples offers to explicate the intricacies of CKD. This is necessary for determining appropriate, meaningful and sustainable actions.

Research Questions: *What are the living stories of people with kidney disease within a First Nation community?*
How does the sweetgrass and porcupine quill birch box methodology foster the interpretation of the living stories in relation to kidney disease?

Methodology: A qualitative Indigenous Methodology is utilized. Through the analogy of a sweetgrass and porcupine quill birch box, the methodology of this research will encompass Indigenous traditions. The methodology is to engage full participation by the community in that it emerges from the community's contextual cultural traditions and values. This approach further supports trust and engagement where a colonial history has previously created distrust in Westernized research methodologies.

Methods - Dreams and sharing circles – unfold the *living stories* - beyond that of being lived but continues through the past, into the present and beyond, is not linear but transforms in relation to all the living and non-living immersed within the cosmos. This speaks to a living story with no beginning or ending, like a web that continues to spin, linking with ancestors, animals and the land, living and breathing outside the European concept of time. The living story transpires from the dreams and sharing circles to express the methodology rooted within an Indigenous way of being. The *living stories* are expressions of the relational interconnections between peoples, cultures, history and the land.

***Relational Axiology* –** heartfelt relations find healing like the sweetgrass that weaves us together and the grandfather teachings of wisdom, love, respect, bravery, honesty, humility, and truth. The sweetgrass and porcupine birch box has at its crux the value of respect, where all dialogues between people and nature are respected, linked and deciphered through the virtues inherent within the grandfather teachings. The birch bark in its representation of truth for example signifies a way of perceiving what truth means to a people. The meaning of truth extends beyond the western concept of facts to embrace the land and everything on it as a living entity. An ethical methodology requires congruence with the ontological, epistemological and axiological uniqueness of Indigenous peoples within their contextual experiences.

***Ontology and Epistemology* -** When the sweetgrass is smelled the beautiful scent can only bring positive thoughts that cast away the dark lonely images. The birch box is the delicate and versatile strength that may come to mean the ability to protect, transform and see new perspectives. The birch bark has been used ceremoniously in the past to encase the deceased. Together the birch bark and the sweetgrass, a sacred medicine, symbolize all earnest and good things and healthful ways of living. The porcupine quills represent the spirit animals and the clans that create a purpose and direction through our living within our relations. The four points of the blackened flower quills signify the four directions further reinforcing the interconnectedness and guidance through the land and mother earth. The circular shape is that of the universe and father sun. Inside the box in the open space underneath the lid is the space that contains the dreams that come to us in our sleep and visions that behold our collective paths, destinies and the unknown mystery.

Preliminary Findings *– open and accepting views towards transplants, needing improved access to health care and dialysis directly within the community; seeking medical and health support that is culturally safe and receptive to Indigenous ways of knowing and being.*
N= *10 participants; 3 sharing circles. The study has evolved into an ongoing "Kidney Circle" offering continued support within the community.*