

SYILX HEALTH AND WELL-BEING IN PALLIATIVE CARE

by

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B.Sc., University of British Columbia, 2007

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

in

THE COLLEGE OF GRADUATE STUDIES

(Interdisciplinary Studies)

THE UNIVERSITY OF BRITISH COLUMBIA

(Okanagan)

April 2018

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Abstract

This thesis examines stories shared by Syilx community members in accessing primary healthcare and palliative care within rural and remote hospital systems in the North Okanagan. This thesis reviews the literature on Aboriginal palliative care delivery in addition to analyzing individual interviews with Syilx community members and review of traditional Syilx story. The purpose of examining these stories is to identify gaps within current systems of care that Aboriginal peoples navigate. This research discovered that Aboriginal palliative care models in British Columbia are limited for the diverse Aboriginal communities. This research also notes that Syilx communities want to engage healthcare providers in meaningful conversations to help advance understanding of traditions and cultural practices that facilitate health and wellness for Syilx communities.

Lay Summary

This research examines narratives shared by Syilx community members in accessing primary healthcare and palliative care within rural and remote hospital systems in the North Okanagan. The purpose of this work is to give voice to Aboriginal patient and family experiences. Palliative care is limited in terms of Aboriginal involvement; this research initiated conversations on what health and wellness means within Okanagan communities.

Preface

In this dissertation I have not used the standard font for APA style and have used Aboriginal Serif. Aboriginal Serif was used to accommodate the use of Nsyilxcən language in the document.

As a graduate student researcher on the Canadian Institutes of Health Research (CIHR) funded grant titled ‘Establishing Cultural Safety and Effecting Change for Aboriginal Healthcare in the Urban Centres of the Okanagan Valley’ I worked with the Cultural Safety Research team to examine experiences in healthcare by both providers and patients. The Principal Investigator for this project was Dr. Rachelle Hole and produced the article ‘*Visibility and voice: Aboriginal people’s experiences of culturally safe and unsafe healthcare.*’ (2015). Research interviews included in this dissertation were completed during this project

Acknowledgements

Limlmt i?_snqsilx^w. Limlmt i?_syilx. Limlmt i?_tmix^w. Limlmt i?_siwłk^w. Limlmt i?_tmx^wula?x^w.

Thank you to my family for your support. Thank you to the Okanagan people and those who will come after. Thank you to all living things who help us to live. Thank you to the water who is life itself. Thank you to the land where we will one day again rest.

Glossary

Awtmasqilx^w - the people who come before the time of k^wa?sic

Captik^wł - formal story

C'askʔaknaʔ - chickadee

Kákátəłqs - horsefly

Kəkwap - dog

Ki?lawna - grizzly

Kłq^wʔaylx^w - name, grayhorse

Kłtərar- the continuous unwinding motion of thread used to describe the unwinding story through time

K^wa?sic - the time known as 'hereafter'

K^wistłtm - naming of a child

K^wulncutn - he/she/it that made themselves

Mənik - dung

Nʔawqnwix^w - process of consensus dialogue for the purpose of resolving a problem

N^włk^włtm - birth of a child

Ntəx^wsiltńs - afterbirth, placenta

Pʔax - to spark to cause light

Qʔsapi - a long time ago

Qʔwɪmiʔst - work that one does in order to put their most confident self-power outward

Scxʔəlxʔaltʔ – the activities that life, health, wellness

Sʔʔaʔcɪnm - deer

Smímay – narrative

Səñkʔlip - coyote

Skəʔtráɪt - responsibility to perpetuate life in a good way

Sqəlxʔɪcawt – native ways/customs/practices

Stəʔsqilxʔw - torn from the earth people, the first people

Stəʔtáɪt - to follow the natural laws and live life in balance

Stəʔəʔlxʔumɪ - woodpecker

Stunx – beaver

Suxʔap - fire

Syilx - ‘dream in a spiral’ people of the Okanagan who come from the stəʔsqilxʔw

Tmixʔw - all living things

Təmxʔulaʔxʔw - the land

Xaʔtmasqilxʔw - ‘those who come after’ people

X^wanəmx^wanəm - hummingbird

ǰ^wylǰ^w - fox

Yəyʔat stim? put - all things just right/alright/ok

Dedication

This thesis is dedicated to Syilx families and to those who are yet to be.

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1 Syilx Health: Okanagan Health

1.1. Introduction

1.1.2. Positioning of Self

Wáy xast s̓əłxʔalt iskwist Čə́tups. In mistə́m Paul Alexis, in tùm Gloria Alexis. I s̓ə́xpa? twi Murray Alexis, in qaqa? Dora Alexis. In k'ík'w'a? twi Steven Quaw, i stímtíma twi Mary Quaw. Kn tl nkəmapl'qs. My name is Carmella Alexis and my parents are Paul and Gloria Alexis. My grandparents are Murray and Dora Alexis and Steven and Mary Quaw. I come from a place in the Okanagan called Head of the Lake near Vernon, BC.

As a Syilx scholar, my research interests encompass health and exploring the diversity of health research in relation to Syilx knowledge and traditions through language and cultural practices. The transmission of knowledge and tradition through language and cultural practices speak to our everyday experiences and the experiences of the people who came before us. There is knowledge and power in stories, they have the ability to spark change and create new growth.

In this thesis, I explore the stories of Syilx community members in accessing primary health care services and stories of loss at Vernon Jubilee Hospital. In receiving these stories I also give one back to the community.

In the Fall of 2014 my partner and I welcomed our first child, Kłqʷʹaylxʷ, at Vernon Jubilee Hospital. The birth of our son, or n̓kʷiltm, came after months of preparation by us and our families. We had followed cultural protocols for the duration of the pregnancy and we took the time to write out the cultural protocols that we would be adhering during labor and delivery in our birth plan. We met with staff at Vernon Jubilee Hospital prior to delivery to tour the Maternity ward and discuss our cultural requests. We let the staff know that there were three significant cultural protocols which we wanted to respect during the n̓kʷiltm. They included: that the father be the first person to touch the baby during the birthing process, that the first words spoken to the baby be in Nsyilxcən, and that the afterbirth, or n̓təxʷsilt̓s, be returned to us for ceremonial purposes. During our meeting with staff at VJH they let us know that the afterbirth would be returned to us after 48 hours had passed. We left copies of our birth plan with the staff and also brought the paperwork with us when we went to be admitted.

On Saturday October 25th 2014 my water broke in the early morning and we made our way to the hospital. Our family joined us for the labor and our baby, Kłqʷʹaylxʷ, joined us late that afternoon. We had minor complications as

Kłqʷaylxʷ had shoulder dystocia and I received stitches for tears. We reminded the staff in the delivery room that we were going to take the ntəxʷsiltńs and they labeled the bag that we would take with us when we were discharged. We were kept in the hospital beyond a few days, as Kłqʷaylxʷ was a little jaundiced and needed UV light therapy.

This was not an inconvenience as we were following the custom of ten days of rest and seclusion and we made good memories of our first few days together.

During those first days we finalized preparations for the ceremonial burial of the ntəxʷsiltńs and the kʷistiltm, baby naming ceremony. The kʷistiltm marks the end of the ten days in seclusion and represents the ten months that the baby has grown and signifies the beginning of the new life. It is at this time that the community comes together to meet the new baby and greet the baby by name.

When it came time to be discharged from the hospital we requested the ntəxʷsiltńs and the nurse on duty let us know that we would have to return the next day to collect it. We left the hospital and returned the next day to pick up the ntəxʷsiltńs as planned. When I approached the nurses on shift they let me know that there were no ntəxʷsiltńs in the fridge with my name or delivery date on them and that I should have left the hospital with it.

I remember feeling scared and confused at first, I had trusted the process and the rules that the hospital had put into place. After those first few minutes when it became clear that I was not going to take home our ntəx^wsiltñs I felt hopeless. The nurse let me know that they were going to look for it and that they would call me and follow up. I felt scared and confused that this was happening to us and I remember crying in the hallway and becoming hysterical. The nurse on duty had me move to a chair in a small room while she went and spoke to the other staff on duty. I sat in that room and cried and phoned my partner who was in the car below with Kłq^wʔaylx^w. When I waited for the nurse to come back I looked around the room and I saw little baby hats and outfits that were held to be given to parents that lose their little ones. I can remember thinking that this loss is not a loss like that one and we still have a lot to be grateful for.

We ended up leaving the hospital that day without our ntəx^wsiltñs and I cried for a long time for it, it felt like something left unfinished. It was hard for me to think about those ten months and preparing to place that piece of him and me in a specially chosen place and in the end knowing that we will never know what happened to the ntəx^wsiltñs. Placing the ntəx^wsiltñs into the ground signifies one of the first connections to place that you make for your little one. The place

you select to bury the ntəx^wsiltñs signifies a tie to the land, which the new baby will always recognize as home. Losing the ntəx^wsiltñs meant that we could not provide one of those first connections to place for our little one.

To some people the ntəx^wsiltñs holds no purpose once delivery has occurred, it becomes medical waste. It is sad for me to think about someone throwing it out as medical waste because it was never garbage to us. We received a letter and small gift from the Manager of the Maternity ward at VJH apologizing for the incident and letting us know that an investigation had been completed and changes had been implemented to ensure that the ntəx^wsiltñs being kept for pickup and those being held for later discard were being kept in separate refrigerated locations.

It's been three years since our son was born and in that time there have been some changes I have seen within my family and our interactions with the hospital. I delivered once more at VJH and two of my sisters have delivered three times there since 2014. During each of these deliveries we have not allowed the ntəx^wsiltñs to leave the room after delivery, each time we have brought our own cooler and have kept it on ice within the room until our discharge. We have no reason to believe that the changes within the system are

not working but at the same time we are not willing to take a chance on losing the opportunity to tie our babies to the place that we come from.

Prior to this experience I had worked with the Cultural Safety Research team which included select employees from Vernon Jubilee Hospital on the Canadian Institutes of Health Research (CIHR) funded grant titled 'Establishing Cultural Safety and Effecting Change for Aboriginal Healthcare in the Urban Centres of the Okanagan Valley'. The Principal Investigator for this project was Dr. Rachelle Hole and produced the article '*Visibility and voice: Aboriginal people's experiences of culturally safe and unsafe healthcare.*' (2015).

As a student researcher on the team, I worked with the collective to examine local stories from Aboriginal patients of their experiences accessing care at Vernon Jubilee Hospital and from Healthcare providers in their work with providing services to Aboriginal peoples. The narratives from Aboriginal patients covered a variety of issues and concerns. People want to be heard. People want to be respected. People want to be included as active participants in the care they receive. Many of the stories that were shared with the team speak to negative experiences and the need for reinvisioned partnerships between healthcare providers and healthcare consumers.

Creating opportunities for positive experiences in accessing primary health care for Syilx people requires a multifaceted approach that is rooted in continuous ongoing dialogue between healthcare providers and community members. It is important for community members to feel that healthcare systems can respond to their cultural needs. Access to medical services is difficult to navigate and those with historically traumatic experiences of modern medicine, particularly Aboriginal populations, are especially vulnerable to experiencing poor care.

This research examines stories shared by Syilx community members in accessing primary healthcare and palliative care experiences within rural and remote hospital systems in the North Okanagan. The purpose of examining these stories is to identify gaps within current systems of care that Aboriginal peoples navigate in accessing care and palliative outcomes. In identifying these gaps healthcare providers and researchers can better position future work in improving systems of care and positive health experiences. This research includes an analysis of current palliative care literature in addition to including community members' stories of accessing care and palliative experiences. This work also includes an analysis of traditional Syilx story, *captikwł*, which serves to highlight the importance of traditional knowledge in Syilx ways of understanding and living health and wellness.

1.2. Theoretical Approach

Syilx people are connected to the land and its resources through culture and language. Good health and wellness are the outcomes of maintaining connections to land and to place. As communities grow, connections to place get learned and reinforced through family knowledge- through story, through language. There is a continuous cycle of renewal that brings balance to Syilx communities. Through culture and language Syilx communities experience growth and change.

This research illustrates the use of *captikʷł* within Syilx communities to transmit values and beliefs of Syilx health and wellness through family systems. This research also analyzes *captikʷł* through Syilx cultural frameworks to provide a deeper understanding of health and wellness in Syilx communities. In addition, it also analyzes the provision of palliative care within the primary health care system utilizing local community narratives and current literature.

This research plays an important role in the creation of transformative Indigenous health research through cross-cultural collaborations. Kovach notes that as Indigenous researchers we have an ethical responsibility to follow the community's protocols for Indigenous research as we work to initiate change not only on a community level but also within ourselves as individuals (Kovach, 1964). Transformative research within

local Syilx communities requires a collective approach and the direct involvement of Syilx community members as researchers and expert knowledge holders.

In addition, this thesis utilizes individual interviews and an overview of current literature on palliative care. This research examines gaps in services for Syilx community members and provides the opportunity for knowledge transfer and personal reflection for healthcare providers and researchers. This research is not intended to provide a comprehensive list of all healthcare discrepancies or shortcomings within palliative care services but examine current experiences of Syilx community members in accessing care and potential areas for knowledge exchange and increased communication.

Syilx language and cultural teachings emphasize the importance of wellness in relationship to place which juxtaposes with western ideas of health that focus primarily on the physical being; introducing medical providers and researchers to Syilx concepts of health and wellness will provide constructs for care that is more inclusive leading to improved health outcomes and experiences within medical systems. My thesis questions are (1) how will cultural teachings emphasize the importance of wellness in relationship to place? (2) How do these teachings juxtapose with western ideas of health? (3) How will introducing medical providers and researchers to Syilx concepts

of health and wellness provide constructs for care that is more inclusive, leading to improved health outcomes and experiences within medical systems?

1.3. Positioning Syilx Epistemology in Relation to Health

This thesis considers a question of life- *stim i_scx^walx^walt?* That is, what makes up the elements of life, as we know it. Within Syilx communities, this is the continuous cycle of life and renewal of all living things. As time moves forward new becomes old and from death comes new life. Health and wellness within Syilx communities is rooted in mindful practice. The choice to live as a Syilx person by practicing Syilx culture and traditions is a choice that must be made every day. The ethics that comprise Syilx values and beliefs reflect the balance of environmental systems and the checks and balances in which those systems regenerate and renew. It is through language and cultural identity that Syilx communities experience good health and wellness (Armstrong, 2010).

Expression of cultural identity and knowledge is shared through family and communities through voice: the singular prayer, song, story. Story within Syilx communities is important to maintain connections to the land and to each other. In noting the importance of story within the local community, this research highlights the importance of Syilx voice through selected narratives that speak to the lived

experiences of navigating rural and remote healthcare systems and hospitals. Story connects past generations to future ones and is an integral part of Syilx communities past and future as evidenced by the history of oral literature that has survived to present day.

1.4. K^wu_awtmasqilx^w: we are the people of this land

From the beginning of time, Syilx have lived on this land. Our stories tell us that the first people learned to live off the land through their dreams. Syilx storyteller Harry Robinson's 'The First People' speaks of the creation of the world by K^wulncutn (the one who made himself/herself/it). K^wulncutn represents the beginning of all existence and later the start of our human existence (Robinson, 1989). All things are from one source, all things are interconnected.

The nsyilxcən word *Syilx* denotes specific responsibilities within the Okanagan community. The word *Syilx* is a command in nsyilxcən from the beginning, from k^wulncutn, that speaks of the responsibilities that collectively 'we', Syilx people, have to the land. The word *Syilx* can be translated as responsibilities that individuals have to take care of this land and its people through songs, prayers, ceremonies, language, and traditional practices. Syilx captik^wł tell us that the Syilx come from the first people called the stəlsqilx^w, who were named such because they were torn from this earth.

The st'əlsqilx^w learned through their dreams to live on this land and their families grew to become the xaʔtmasqilx^w, called those who come after sqilx^w. Syilx recognize that now is the time of the awtmasqilx^w. They are the sqilx^w who come before the time of k^waʔsic. K^waʔsic refers to a time in the future that is known as 'here after' (Armstrong, 2008).

Story or narrative known as either captik^wł or smimay have the ability to give us clues as to how to respond to changing health of communities and the land. Captik^wł and smimay are oral stories, which show specific knowledge and understanding of place and the life cycles of that place. Captik^wł speak to the natural laws, which form the basis of Syilx traditional governance. The natural laws spoken through captik^wł are represented through teachings that people are connected to each other in diverse ways (Armstrong et al., 1994). On a basic level they relate environmental knowledge and when analyzed further they reveal the dynamics of environmental interrelationships living and growing in Syilx territory. Captik^wł teaches the people how to live in balance with self and the natural world by showing the outcomes of specific actions related through relationships amongst the tmix^w (Armstrong, 2010).

Consider the Syilx concept for living things, tmix^w- are all living things in this world. Tmix^w can be envisioned as the balance of life, which exists within beings that

connects living units to each other. Armstrong notes that *tmix^w* can be thought of as a number of strands each fanning out from one source. Together they grow as one unit but individually they still remain singular strands. All *tmix^w* live on the land, *təmx^wulaʔx^w*, which translates as life-force-place. *Tmix^w* are not elements such as rock, air, fire, water, or earth. Rather *tmix^w* are living things with the ability to regenerate. *Tmix^w* represent the cycles of life, continuous regeneration through the cycles of life and death and can be thought of as one of the broadest expressions of health (Armstrong, 2010). Armstrong describes a Syilx Okanagan environmental ethic as the recognition that all *tmix^w*, all living beings, have the right to regenerate and to participate in the fluctuating life cycles that exist within Syilx territory (Armstrong, 2010). The collective ability of the *tmix^w* to regenerate is perpetuated through the interrelationships.

There are different types of *captik^wł* and this thesis examines the *captik^wł* of the *tmix^w* or the ‘animal people’. These stories are called the ‘world-before-humans’ stories and in these stories the *tmix^w* are tasked with collectively resolving a problem. The *tmix^w* work together to solve the problem for the survival of the humans who are coming to live on the land. For the purpose of the story the *tmix^w* take on forms that we now see as mammals, plants, or insects but as noted by Armstrong, “*captik^wł tmix^w*

are neither human nor animal but somewhere in between” (Armstrong, 2010, p.93).

Armstrong notes that understanding of *captikwł* theoretical framework is important to a deeper understanding of Syilx knowledge expressed through *captikwł*. *Captikwł* theoretical framework defines the parameters through which traditional knowledge is interpreted and analyzed. It positions the characters as they are found within nature as apart of a whole system (Armstrong, 2010, p.94). Analyzing *captikwł* within current constructs can provide solutions to problems that are culturally based, and recognize change and growth within systems while maintaining and preserving traditional practices.

1.5. Syilx Governance & Health Ethics

Syilx Okanagan ethic is about respect of all life forms through all life stages and the knowledge that the continuous regeneration of all living things is dependent on the other. With this understanding, the ability of the collective to regenerate guides Syilx behavior towards *tmixw*. All life forms must live in balance of the system to ensure its ongoing system wide renewal. Syilx environmental ethics occurs within the individual through continuous respect and recognition of all living beings to continue through their life cycle (Armstrong, 2010). This daily action is explained through “*kłtərar*- the continuing motion of an unwinding bond-thread used to describe the unwinding story

through time as the foundation for Syilx thought and in being within the laws of Syilx existence.” (Armstrong, 2010, p.43-44).

Syilx traditional governance is built on the ethics and teachings of Okanagan *captik^{wł}*. They are our first stories, which speak to the natural laws of this land through metaphor and allegory. *Captik^{wł}* are oral history, they represent the natural laws of syilx people and life lived through those laws (Armstrong et al., 1994). The laws of the *captik^{wł}* are represented through teachings about the lives of the *tmix^w* and the land. As community members, we learn about the world around us through *captik^{wł}*, the stories we learn teach us the importance of understanding the diverse connections that human beings have with the environment and how to live in balance on this land (Armstrong et al., 1994). The natural laws of the Syilx largely emphasize the well-being of all community members, both Indigenous and settler, within Okanagan territory. As Syilx we are encouraged through our natural laws to live with a real respect for all visitors within our territory. The idea of ‘otherness’ is discouraged while ‘wholeness’ is emphasized. As community members we are reminded through the customs of our traditional governance systems to reflect on the health of the land as the health of all of the people and animals living on it. Collectively our spiritual and

cultural responsibilities to our territory are just as important as our responsibilities of taking care of one another.

The participatory nature of traditional Okanagan education reflects one of the foundations to our traditional governance system. This idea of community members as participatory governance is strengthened through the participation of all community members in the traditional Okanagan process of consensus dialogue called *nʔawq̓nwixʷ*. The highly structured process of the community gathering together to make decisions is represented through the visual metaphor of drops of water dripping into people's minds leading to a group understanding. The *nʔawq̓nwixʷ* process is integral to traditional Syilx governance; it places children and the next generation at the heart of the decision-making process. This process was historically used by Syilx people to connect all generations through a sense of responsibility not only for their own well being but also for the well being of future community members (Armstrong et al., 1994). Current applications for *nʔawq̓nwixʷ* process extend beyond components of traditional governance. For instance, applying *nʔawq̓nwixʷ* to issues of concern can provide clarification, and is useful as a tool for critical analysis from an Indigenous perspective. The process of *nʔawq̓nwixʷ* is illustrated later in the *captikʷł* of how fire was stolen by the animal people.

1.6. The Health of the People is the Health of the Land

Current medical systems reflect the history of settlement within the Okanagan Valley both in structure and location. The foundations of those settlements are built on colonial values and beliefs, an idea that the settler himself is the absolute beginning, “...This land was created by us...if we leave, all is lost...” Frantz Fanon, 1963, p.51).

The values and beliefs that created those medical institutions are continuously reflected and reinforced through the bureaucratic systems set in place to support them. The transformation of those institutions to reflect Syilx concepts of health and wellness within communities can be thought of as a decolonization process.

There are many ways to pursue decolonization of both the self and collective. Fanon notes that the practice of decolonization is the active practice of putting the last first and the first last (Frantz Fanon, 1963, p. 37). The transformative work of decolonization within healthcare systems is not explored in depth here, but it is one path to Indigenous communities achieving balance and justice. From Indigenous perspectives, the process of decolonization can be seen as “...the intelligent, calculated, and active resistance to the forces of colonialism that perpetuate the subjugation and/or exploitation of our minds, bodies, and lands, and it is engaged for the ultimate purpose

of overturning the colonial structure and realizing Indigenous liberation. (Waziyatawin & Yellow Bird, p.2)

Within Syilx communities, cultural traditions and practices are expressions of knowledge of the self and/or family whether that knowledge is explicit or subconscious. Armstrong notes that Indigenous expressions of knowing and being can be called *i?_sqəlx^włcawt* which is ‘our native ways/customs/practices’. The term refers to the things we do as specific individuals within our culture as a deliberate part of our existence (Cardinal & Armstrong, 1991). The idea that our ways/customs/practices are actions rooted in historic practice that reflect the individual choice of that way of life is reflected through language and story.

Within Syilx communities the ability of the self to dream reflects the infinite potential of what can be achieved. The Syilx word for people is *sqilx^w*, which translates as “the dream in a spiral”. The self is acknowledged to have the ability to learn lessons and solve problems through dreams and the possibility of creative thought (Cardinal & Armstrong, 1991). The potential of an individual is not considered without the balance of the system.

Systems balance themselves unless they are pushed beyond the limits of regeneration. The idea that thresholds of systems must be maintained for all life, is

reflected through- yəyʔat stimʔ put. This can be translated as the idea that all things are alright/okay/just right. Armstrong notes that this Syilx phrase conveys the principle of deliberate non-destruction, it is a reminder to be aware of and to be protective of the sensitive nature of interrelationships between all living things.”(Cardinal & Armstrong, 1991).

The ability of the Syilx to create physical tangible objects from the imagination of dreams is referenced in captik^{wł}. For example, the Syilx captik^{wł} of how fire came to be on this earth can be seen as a representation of the power of action that can be achieved through good health and wellness. Within this captik^{wł}, the animal people approach the problem of the survival of the people-to-be with what can be termed as q^{wł}łmiʔst. Translated this refers to the work that the individual does in order to “put your most confident self-power outward” (Cardinal & Armstrong, 1991).

On a community level, Armstrong notes that this refers to a collection of skills that an individual must employ in a group/individual setting to achieve positive outcomes. These skills are not limited to one aspect of the physical, mental, spiritual or emotional. It is the idea that collectively and/or individually, people can in a deliberate reflective process call upon whatever aspects of the self that are needed to act and will

do so without hesitation or question. This Syilx word is referenced here to note that this work reflects research of serious consequence (Cardinal & Armstrong, 1991).

Good health and wellness within Syilx communities is the result of balanced activities/choices. The continuous regeneration of Syilx communities is the direct result of four main activities including all activities required to maintain human life or *i?_scx^wəlx^wáltət*. The next is- *i?_stəłtáłtət* or all activities related to learning and living by the natural laws that keep systems in balance. The activity or *i?_skəłtrártət*, is the responsibility of the self to perpetuate human life in a good way. Lastly, the fourth activity or *i?_sqəl^włcawtət* is to practice language and culture and spiritual practices so that Syilx communities can continue to grow into the future within a system in balance with the natural world (Cardinal & Armstrong, 1991).

1.7. Methodologies

1.7.1 Literature Search

The literature examined within this research was limited as the research areas are underdeveloped and within the area of Syilx health and wellness literature almost does not exist as Syilx stories have only been recorded within the last two hundred years by anthropologists, ethnographers, linguists etc. The Syilx people have a rich history of oral literature and this is noted by prominent Syilx scholars and authors such as Dr.

Marlowe Sam, Dr. Bill Cohen and Dr. Jeannette Armstrong. This research includes one Syilx captik^{wł}, ‘How Fire was Stolen’ a version of how the animal people prepared for the people-to-be by Syilx storyteller Billie Joseph.

The literature examined included that on palliative care within Canadian medical systems specifically British Columbia. Search terms were selected to reflect the community of people who access care within hospital systems in the North Okanagan, which includes a variety of Indigenous peoples and so the search term ‘Aboriginal’ was utilized. Search terms included: Aboriginal people(s) and/or First Nations, Palliative Care, Rural and/or remote hospital systems, British Columbia and/or Canada. The main search terms used are ‘Aboriginal’ and ‘palliative care’.

1.7.2 Individual Interviews

The CIHR funded grant ‘Establishing Cultural Safety and Effecting Change for Aboriginal Healthcare in the Urban Centres of the Okanagan Valley’ included both group and individual interviews as part of the analysis of Aboriginal experiences in accessing primary health care in the North Okanagan, specifically through Vernon Jubilee Hospital (VJH). The research collective was able to recruit 41 participants, which included a range of Aboriginal people, and/or families who have received care at

VJH, Health care providers responsible for providing services to Aboriginal people in the community and Health care providers at VJH.

As this research examines Syilx constructs of health and wellness, I examined interviews completed by Syilx community members only. In addition, this research only includes interviews that spoke to palliative experiences and/or death within VJH or local healthcare systems. This includes excerpts from 3 individual interviews and excludes 38 group/individual interviews.

Chapter 2 Palliative Care Literature Review

2.1 Introduction to research topic

A person may “die of loneliness because nobody [will be able to] visit [them].”

(Castledon et al., 2009, p.9).

This literature review examined palliative care services in British Columbia and Canada for Aboriginal populations. It includes both peer reviewed and professional reports. These articles indicated a number of broad issues while providing concrete examples for the development of new way forward.

Researchers identified the following areas of concern for the provision of palliative care within rural and remote communities and those include: undeveloped/ underdeveloped medical systems; lack of knowledge of local cultural practices in terms of the provision of palliative services that are positioned in terms of place; lack of adequate trainers or training opportunities in learning to provide palliative services within Aboriginal communities. Lastly all of the researchers provided direct examples of provisions and/or structures that need to be changed for the creation of palliative services that meet the needs of both the individual and the family. The literature on health care services illustrates the need for innovative models of service provision and

ongoing evaluation of those models in order to effectively address the unique aspects of palliative care in rural and remote settings (Robinson et al., 2009, p.256).

While the research reviewed identifies a number of disparities there is limited writing that speaks to the positive aspects of palliative care experiences for Aboriginal families. Indigenous communities have strong histories of resilience and there does not appear to be many pieces that examine sources of resilience within palliative services and how to recognize and affirm colonial histories within institutions in a good way.

2.2 Current Medical Systems

Describing current Palliative care services within British Columbia requires consideration a number of factors encompassing but not limited to social, political, cultural and geographical. BC is home to a rapidly aging population, which in turn is straining age related services- palliative care included (Crooks, 2009). However, this is not a trend unique to BC as families in need of palliative care is increasing world-wide because people are living longer with a chronic or terminal illness than at any other time in history (Kelly, 2007). While age related resources are being strained it should be noted that palliative services are required within communities across a variety of age categories.

Researchers have produced reports that speak to the history and development of palliative care in BC (Crooks, 2009). The medical system within British Columbia was restructured in 2001 to produce five regional health authorities. This system was created in an effort to streamline access to services and create an equitable system of access to care supported by local and regional administrations (Crooks, 2009). One of the shortcomings in the creation of health regions is that palliative care has been prioritized differently throughout the province leading to different experiences across regions (Crooks, 2009, p.2).

British Columbia is home to approximately 196 000 Aboriginal peoples representing more than 30 distinct cultural groups. Research indicates that palliative care services in BC are unevenly distributed across the service areas with most services located in larger urban centres. General practice physicians take on the majority of palliative care in Canadian hospitals (Castledon et al., 2010, p.484). In 2006, the BC Ministry of Health released a framework on palliative care, which identifies key stakeholders for the provision of palliative care in the province.

With regards to the development of palliative care programs there are three health care institutions in charge of writing and developing palliative care policy and practice within BC, they include the BC Ministry of Health who are responsible for legislative

changes to improve end-of-life care, the Health Authorities who are responsible for the delivery of services, and the health care providers who are responsible for providing services and support (Crooks, 2009, p.2).

2.3. Problems Identified within Medical Systems: Undeveloped/ underdeveloped medical systems

Advances in medicine and preventative health measures coupled with social and environmental factors have created situations in which Aboriginal peoples live longer, but with more chronic and degenerative diseases. It is theorized by Castledon et al. (2010) that living with chronic and degenerative diseases increases the possibility of needing palliative services which creates problems for Aboriginal patients and family members as the only palliative care services available may be outside their home communities and/or located within hospitals (p. 483-494). The continued higher mortality rate and growing chronic illness rates among Aboriginal peoples suggest a need for culturally appropriate end-of-life health care delivery (Hampton, Baydale, Bourassa, McKay-McNabb, Placsko, Goodwill, McKenna, McNabb, & Boekelder, 2010, p.7).

Researchers, Crooks et al. have noted that individual interviews in BC along with analysis of literature have shown that there have been shifts within palliative care priorities and that there remain struggles in rural and remote locations to providing quality palliative care programs/services (Crooks, 2009). Further, research has examined the delivery of palliative services within the different regions and current barriers within systems (Castledon et al., 2010). For instance, Williams et al., identified a number of historical structural systems in place that prevented the integration of healthcare providers into long standing established systems of care (Williams et al., 2010, p.13).

It is important to explore the model for palliative care service delivery within medical institutions to ensure that Aboriginal patients and their families receive services that reflect their unique needs. Aboriginal communities within British Columbia are often located in rural and remote locations. Researchers have discovered that with regards to rural palliative care services- average final hospital stays are longer in rural hospitals than in urban ones and rural residents are more likely to die out of hospital, and models of care delivery designed and implemented in urban centres may not provide the support/services needed in rural communities. (Crooks et al., 2009). Also, professional interpreters/advocates play important roles with patients and family

members and healthcare providers as they help to educate, advocate and mediate during the process of accessing and receiving palliative care services (Kaufert, 2010, p.412).

From their community interviews, Castledon et al. were able to identify four important keys for the enhancement of palliative care services for Aboriginal clients that can help to create 'good deaths' for families accessing services. "These four keys include: (1) earmarking resources to support culturally specific practices (e.g. smudging); (2) providing culturally safe care that supports people in claiming and embracing their Aboriginal identity at end-of-life; (3) giving care in spaces that do not re-institutionalize Aboriginal people; and (4) and offering training to formal and informal service providers regarding cultural practices in death and dying." (Castledon et al., 2010, p.488-489).

Palliative care is integrated into rural health services and research on rural palliative care reflects that same problems and practices as delivery of other health services in rural and remote locations (Kelly, 2007). The literature reflects that no models have been developed that conceptualize the development of rural health or palliative care programs driven by local healthcare providers (Kelly, 2007).

Hampton et al., note that results from their research add to a previous study, which showed that there are barriers to providing culturally, appropriate end-of-life care to Aboriginal families in a hospital setting (Hampton et al., 2010). There are currently no standards within Canada for Aboriginal palliative care which means that Aboriginal patients and families access the same services as other Canadian patients- services that were not developed with Aboriginal people's history or cultural needs in mind (Castledon et al., 2010). Researchers note that Aboriginal populations "...often lack recognition of their desire for self-determination and autonomy in terms of how they engage in both living and dying (Castledon et al., 2010, p.483)

A major barrier to Aboriginal populations accessing and receiving palliative care services is the disconnect between Western bio-medicine-oriented models and Aboriginal cultures. The disconnect between the two systems results in "...communication difficulties, discrimination, and institutional policies that interfere with traditional responsibilities" (Hampton et al., 2010, p.12). Disconnect between Western medical models and Indigenous culture and language is further compounded by a lack of knowledge of Aboriginal cultural practices in terms of palliative care services.

Kelly & Minty note that there are generalizations about Aboriginal peoples that extend to healthcare institutions- for example, there is a belief that all Aboriginal peoples smudge as a part of spiritual practice which while true for some is not true for all (Kelly & Minty 2007). In addition, there are assumptions amongst healthcare providers that spiritual practices are not integrated fully into Aboriginal communities, as they do not see them practiced. Healthcare providers understand that Aboriginal peoples have unique needs but there is a lack of understanding as to what those needs entail (Castledon et al., 2010)

Studies indicate that cultural minorities under utilize health services and this is in direct relation to cultural and conceptual differences in what health means to the provider and to the patient, there are systemic barriers built into healthcare institutions that inhibit access to care (Castledon et al., 2010, p.488). Addressing barriers within healthcare systems requires analysis of current systems as unique units. Developing palliative care services can build on existing resources and there are a number of suggestions from researchers and community members as how to achieve that (Kelly, 2007). Crooks et al., note that bringing a larger group together to speak to client needs and preferences can also help to identify gaps in local services, and can facilitate

collaboration and the coordination of efforts that strengthen local systems (Crooks et al., 2009 p. 10).

2.3.2 Problems Identified within Medical Systems: Lack of knowledge of local cultural practices; the provision of palliative services that are positioned in terms of place

The Western biomedical understanding of dying and death is juxtaposed with traditional Aboriginal ways of understanding dying and death (Hampton et al., 2010).

This gap in cultural understanding between healthcare providers and Aboriginal patients and families needs to be addressed for the development of palliative care services. There is a diversity of beliefs within Aboriginal communities and this is in relation to traditional or adopted practices or a combination of both (Kelly & Minty, 2007). As a reflection of a lack of understanding of Aboriginal peoples cultural needs and practices many palliative care systems lack the required components to accommodate cultural practices and/or needs (Castledon et al., 2009).

A lack of understanding about cultural practices and/or needs amongst Aboriginal peoples is also extended to access of services and how and why palliative care services are accessed by Aboriginal patients or not. In a study of healthcare

providers by Castledon et al., healthcare providers made contradictory statements about where Aboriginal people go to die or be cared for while dying and there is an idea that Aboriginal peoples leave an area with palliative care services when facing death. A healthcare provider says “ [Aboriginal people] go back to where they come from...I’ve seen it happen a couple of times where the services become increasingly difficult to access, and they just they return to the place familiar to them...we don’t keep them here...But there’s definitely a pattern in this community where [Aboriginal] people leave the community.” (Castledon et al., 2010, p.487). In this study, other healthcare providers indicated that some Aboriginal patients will return to their home reservation but most do not (Castledon et al., 2010).

The physical place of death is an important factor in the experiences of end-of-life care for Aboriginal patients and families (Robinson et al., 2009). As there are many Aboriginal patients and families who push to remain in their homes or home communities for as long as possible it is important to address this in palliative care models that address Aboriginal peoples cultural needs and/or practices (Crooks et al., 2009). Researchers have noted participants speaking to the need for the creation of culturally and physically appropriate spaces for end of life care. Spaces that accommodate the presence of family and friends and allow for traditional and cultural

practices. (Castledon et al., 2009, p.8). It is also important to note that the development of palliative care models need to reflect the history of Aboriginal peoples in Canada with specific regard to the Residential School experience. As Castledon et al. note it is “[v]ery important that palliative areas are physically non-threatening or [as] least institutionalized as possible just because of the residential school experience...and to end your life in a building that may look like that could...really trigger some emotional stuff. Considering the necessary elements for providing culturally safe Aboriginal palliative care, this serves as a reminder that hospitals and long-term residential care units run the risk of presenting more damage than benefit in light of the colonial legacy of institutional settings for Aboriginal Canadians.” (Castledon et al., 2010, p.488).

2.3.3. Problems Identified within Medical Systems: Access to care- rural and remote resources

Research on rural and remote palliative care is limited (Robinson et al., 2009). It is known that geographic inequalities in access to palliative care are expected to rise (Robinson, Pesut, Bottorff, Mowry, Broughton, & Fyles, 2009, p.253). Within BC

rurality and a lack of cultural sensitivity creates barriers to accessing and receiving quality palliative care for Aboriginal peoples (Castledon et al., 2009, p.6).

For northern Aboriginal patients, who represent the most rural and remote demographics, hospital based palliative care services becomes the primary point of contact (Kaufert, 2010). There remains many challenges in addressing rural and remote delivery of palliative care services and they include lack of communication with Aboriginal peoples regarding palliative care planning and inability to remove barriers for accessing palliative care services (Crooks, 2009).

2.3.4. Problems Identified Within Medical Systems: Lack of adequate trainers or training opportunities in learning to provide palliative services within Aboriginal communities.

For many, the moments after an Aboriginal person passes from his or her corporeal state are very sacred (Hampton et al., 2010, p.11). Researchers exploring participant voices on palliative care model gaps include a need for training to discern cultural practices amongst Aboriginal communities, training in cultural sensitivity, and a need for providing communities with equipment and basic training. It is suggested that addressing training concerns would help to remove barriers in terms of palliative care

delivery and provide more opportunities for access (Castledon et al., 2009, p.9).

Training for palliative care delivery occurring both within the region, but within formal educational programs is important to improving access to care (Robinson et al., 2009, p.255).

Building a strong dedicated palliative care delivery team is important to the delivery of services (Kelly, 2007). Growth and development of rural palliative care services needs to include education for providers and access to specialist support from urban areas (Kelly, 2007, p.146). This linkage along with educating providers, patients, families, and community members; building community relationships; advocating for palliative care resources; and building external linkages will help with the development of palliative care services that include Aboriginal perspectives (Kelly, 2007, p.150).

2.3.5. Examples of provisions and/or structures that need to be changed for the creation of palliative services that meet the needs of both the individual and the family.

Researchers identified a number of possible programmatic additions and/or interventions to immediately address palliative care delivery for Aboriginal

populations; they mainly speak to improving communication and dialogue. “Bolger argues capacity development requires broad-based participation, building on local capacities, ongoing learning and adaptation, and long-term investment and integration of activities at various levels to address complex problems” (Kelly, 2007, p.144).

Training was identified as a key step in bridging lack of knowledge of Aboriginal peoples cultural and traditional practices (Hampton et al., 2010). Not only is training identified as a need but also training specifically developed in coordination with Aboriginal peoples perspectives to relay wants and needs (Castledon et al., 2010). For example, Castledon et al., note “...the suggestion was to present Aboriginal palliative care clients with soil from their home territory. Participants who were either Aboriginal themselves or were actively involved with the region’s Aboriginal population identified a number of similar necessary elements in their visions for Aboriginal palliative care. These included having an appropriate physical location and care space, being in close proximity to natural surroundings, being able to practice ceremonial activities while receiving care, having access to traditional foods and the use of traditional medicines.” (Castledon et al., 2010, p.488). Also noted by Elders is that there may be a need to offer foods that bring comfort to the dying person; doing so may bring about spiritual and emotional healing that is not achieved through restrictive

diets meant to prolong the life of that person. Elders noted that care and comfort of the heart and spirit take precedence at the end of life (Hampton et al., 2010, p.11).

To move forward there is a need for shared dialogue and understanding. Communication needs to occur between healthcare providers and Aboriginal communities for the delivery of palliative care services that reflects community values and beliefs. “When skilled health care providers engage at the soul level, it is felt and appreciated.” (Hampton et al., 2010, p.13).

Chapter 3 Interview Results

3.1 Overview of survey

The Cultural Safety Research Project examined health care practices, past experiences accessing care, and expectations for care within 2 units (Maternity and Medical) at Vernon Jubilee Hospital through group and individual interviews of both community members and healthcare providers. In 2010, the project recruited approximately 50 individuals for individual and group interviews. Those recruited included Vernon Jubilee Hospital (VJH) health care providers, Aboriginal people (and/or family members) who received care in the maternity or medical unit(s) of VJH, and other stakeholders in the community with knowledge of Aboriginal peoples experiences in accessing/receiving health care.

There were 41 individuals interviewed in either group or individual settings. Of those 41 participants, there were 31 participants who identified as Aboriginal (First Nation, Inuit or Metis) and 9 of the 31 who identified as Okanagan community members. There were 16 participants who identified as healthcare providers. Of the 41 interviews completed by the research team, I completed 9 individual interviews on the Okanagan Indian Band Reservation. Of these 41 interviews I selected 3 for further analysis. These interviews were selected as the participants were

Syilx community members and shared stories of loss within Vernon Jubilee Hospital. I chose not to include interviews completed by Aboriginal and non Aboriginal participants from the larger sample as they did not speak to Syilx healthcare experiences or share Syilx traditional knowledge. I also, selected not to include interviews which did not address personal experiences with losing family members in the hospital system as this thesis examines current gaps within services provided for end of life care more so than overall services.

3.2 Interview Questions

The interview questions were comprised of open-ended questions and were structured to elicit stories of experiences of either the individual or their family members in accessing care at Vernon Jubilee Hospital. There were different questions asked of community members and healthcare providers. The following excerpts only relay Syilx community members' perspectives and are provided to highlight the range of responses given. I have reproduced whole sections to maintain the integrity of each person's story.

3.2.1 Questions: Can you tell me a story about an experience you or your family member have had at Vernon Jubilee Hospital? What was that experience like for you?

“My first story would be about my grandfather. When he recently went into the hospital [Vernon Jubilee Hospital] he was diagnosed with cancer. It was pretty bad because we thought he was just in there for a minor urinary tract infection. When we found out that he had advanced cancer and that it was all through his whole body; that was tough. We were trying to explain to him what was going on and the doctor was there saying that he had two months to live, sort of a “good luck and we’ll have someone else come in and talk to you” sort of thing. To be honest, we were all bawling our eyes out and my grandpa didn’t understand what was going on. He wanted to know- what did it mean? He said, “Is I’m going...am I going to die?” It was tough to hear that from him and having to explain to him what the doctor had said. That experience, I really remember it. It was really hard knowing that my grandpa was probably not going to leave the hospital after that.” (202).

“With a family member of mine and our past experience at VJH I’m thinking of my aunty passing away or in the midst of passing away. There’s not enough

room for large groups of Aboriginal families. There needs to be a bigger room on each floor, it was really crowded.” (204).

“I’m fifty-five years old and I’ve had a lot of experiences with Vernon Jubilee Hospital for myself and my family. I’ve had pretty good care there. The only thing I had a beef about was I remember my brother, that’s passed on, he went in to see the doctor and they sent him home. His arm was hurting and they sent him home and said there was nothing wrong with it and then all of sudden he goes back to the hospital, they x-rayed it and here it had been broken all that time. I didn’t like that. They said they had to re-break it because it had been left too long but I don’t think my brother let them. That was one of my beefs and I figured it was due to his nationality. That was only one time that the hospital, well a doctor treated us like that. I’ve heard a lot of complaints about that doctor with the Natives and nobody ever did go to him. I’m not going to say his name.” (207).

3.2.1.2 Questions: When you’re thinking about health care what do you think’s important to people? What’s important to you? What’s important about health care?

“The kind of care that we wanted from the hospital staff was for them, knowing what we had found out then [about our grandfather’s terminal illness] is to be a little bit more sympathetic to us. We wanted answers and then to hear from the doctor “oh I’ve got to go and see somebody else, sorry”. I just wish that we could have had somebody else there- a Native Liaison. Someone who could have been with us and who could have stayed behind to talk to us and said something like “Ok, these are your options, this is what we can do, and these are the kind of services you can seek...”” (202).

“The care was exceptional I found, I have no problem with it. It was just the accessibility to get there but the care was great all around. I have no problem with the care my aunt received. In my case the care I wanted when I got to the hospital, it was good. I wanted good quick service.” (204).

3.2.1.3 Questions: Can you tell me about a time when you had to go to the hospital? Did you feel that you got the kind of care you wanted?

“When the doctor first told us we wanted to know more information about it, not just that he’s going to have six weeks to two months to live. We had six weeks with him from then. At the time I wanted somebody there to explain

everything. They told us “in one or two weeks time we’re going to call everyone together and then we will explain everything”. They couldn’t do it right then and that’s what we wanted, we didn’t want to wait two weeks. What they were saying is, it was like he could die tomorrow, that’s how bad it was. So we wanted answers then and we didn’t have any. They [health care providers, doctors, nurses] didn’t provide the type of care that I wanted.” (202).

“I believe in that, common courtesy is what I’m looking for, just common respect towards myself and others or the family. Don’t give me sighs or “do you have to call again?” You know they’re always making up an excuse for unwanted behavior, that’s what I’ve found. Other than that, just treating me with respect I’ve found I want to be treated equal. Not better than some, you know, non-Aboriginal person. I want everyone to be treated equal across the board. The staff at VJH provided the type of care that I wanted. When I got to the hospital it was a smooth transition, I had no problems. The friendliness coming into the hospital, it felt like they were welcoming with open arms but when you’re in there for a week they’re like “come on get better, go home”. I didn’t have any problems with admissions or anything.” (204).

“I had an ingrown toenail and I went to the clinic and they gave me this ointment and told me to wrap it. It wasn’t doing any good and it seemed to me like it was getting worse and more festered. I went to the emergency and this was only last year, end of October or early November, and the doctor comes and looks and, he says, “oh my god, what did the clinic get you to do?” and I told him. They told me that I had to take intravenous antibiotics for four or five days. I couldn’t believe it when he said that I almost lost my toe if I had waited any longer. I couldn’t wait any longer, it hurt so bad so I went into emergency and you don’t want to go to emergency because it’s so long.” (207).

3.2.1.4. Questions: Can you tell me about what happens when you get to the admitting desk at the hospital? What that experience is like for you?

“My grandpa, well he went by ambulance but I mean that was not a problem because he was admitted right away. I remember driving my grandma to the hospital and my grandpa was with me. I parked my vehicle out front but then I had one of these security guys say, “well you can’t park here” and I said “well no my grandma’s sick and I’m bringing her in but my grandpa’s going to be in the vehicle”. I was trying to explain that I’m only going to be however long it

takes to move her in and we got an emergency here so get out of my way, you don't need to be talking, just talk to me after. I explained to him that I'm going to be quick. That was very frustrating; I found the security people there to be rude and not understanding. I now parking was always an issue with us. There wasn't enough handicap spaces there available at the time and still to this day there's not. So both my grandparent's being- one was in a wheelchair at the time and the other had a walker, I found that there was not enough wheelchair space available. It was difficult going to the hospital with my grandparents I had to make sure to call somebody to be there to help me if I had both of them. That was a little tough and that actually took a toll on my grandparents because they said, "well, you know we waited there long enough". My grandpa was a little upset, he could see.. even though they were sick and they wouldn't tell us sometimes they just said "well, if we get there we're going to be waiting a long time anyways so" they wouldn't let us know until they were like really sick. They finally said it was more of a hassle to go there than, than you know, "more of a hassle", that's all they said. They put off going until they were actually really sick and we didn't really know at the time so that was kind of tough." (202).

“When we got to the admitting desk at the hospital it was very confusing because you’ve got two desks right there. They’re so close together and its just like- you’ve got to go over to that desk, and then you’ve got to come back, and then you sign in and then you got to go back to the other desk and then by that time the nurse or whoever you know you’re going to be right back but that nurse takes off and god forbid if you hit that little buzzer, and you know I found it very frustrating because they knew we were there. I mean you could see them back there having a conversation, laughing, having a good time, and yet your grandpa’s sicker ‘n a dog and or your grandma’s throwing up, and you’re trying to explain to them like “OK well can we get him in now?” So admitting them, I think they could find a better way on.. how that little system works right there, ‘cause it, it’s just doesn’t make sense. I don’t know why they have it like that. But I mean if it’s an emergency, you know your grandma is throwing up or you know they’re really sick, just hearing some of the nurses and even some of the doctors all talking about their weekend, how it was, their skiing, whatever they’re doing their new little woofie dog and its so awesome, and just for them to hear, then you’re you know, and I remember hitting a buzzer once, and then you- you can hear somebody there, I don’t know who it

was obviously was a nurse or somebody saying well, yah we know you're there, just wait. I found that rude, and you're just trying to get your grandparents help and they're just back there having a good time. So I find just trying to admit them was difficult. It seemed like it was a little confusing because we had to go back and forth so many times. And small, I find it- the waiting room was...could barely even handle you know five people, especially with wheelchairs I mean and you're all crammed in there, so that was tough."

"The older ladies in the pink suits [volunteers] at the front desk were very helpful. It seemed like they knew what was going on and they were very sympathetic. They were like, "oh I'm sorry to hear about that", and maybe that's all I needed to hear. We never heard anything from the staff but the older volunteer ladies are very nice. It was always good to see a smile from them when you came in because it's not a very nice to place to visit if you have a sick loved one there." (202).

"When you're admitted for an emergency you have to go to one desk and then to emergency and fill those papers out and then bring them back to admissions. So why two steps? Why is that necessary? It was very difficult getting to the hospital and being admitted. The staff were very pushy and rude- "come on,

drop off and get going”. I didn’t like that. I didn’t have a choice; I was being admitted for knee surgery so I had to take it as it was. I don’t know why there are two steps in emergency- you go to admitting desk and then you go to emergency desk and then back to admitting desk. Why create extra steps? Why reinvent the wheel? How many hours in a day are you going to pay for two people to do one job? That’s time and money, its not cost effective. Considering where that person could be- that money could be sent somewhere else.

Experiencing an emergency is not good but my experience being admitted was good.” (204).

“They take the most serious cases first, which I agree with, but I don’t agree with how you are admitted. When you go in to emergency, they give you a paper, then you have to go to admitting. Why don’t they just admit you? You have to go to admitting, get admitted, go over there and you’re back and forth and back and forth. I find it should be different to admit, you know you’re going in right? Do the admitting papers, get them and then go over to emergency and you’re going back and forth. I find it’s too long and I don’t want to go because of that. I’ve got four grandkids and I’ve been up there with the younger ones

and my nieces and nephews and it's long for them. I know there is a shortage of staff, that's another big concern." (207).

3.2.1.5. Questions: Can you tell me a story about what it was like for you when it came time to leave the hospital? What was that experience like? If you can remember who the people involved were? Were you involved in the planning?

"I remember one time that sticks out to me, my grandpa was getting out one time and he had some kind of infection- I think pneumonia. It got really bad and we took him in and they kept him in for quite some time. Maybe about a month just to get him where he should have been, a little healthier and stronger and so I remember getting there at 9:30 for discharge, which was at 11:00, which I thought was lots of time. They were kind of rushing us out a little too fast and saying "well can you dress your grandpa a little faster?" and then they would walk away. It was like- "oh my god, you know I'm trying". So having them rush us out and even having my grandmother in the car at the same time, trying to get my grandpa all dressed and ready to go- I mean he was trying his hardest because he wanted to go so he was helping out too and just having the nurse come in again and say "Ok well you know we need this room, are you going to

be much longer?" Well I'm trying my hardest here and I kind of hinted at her well if you can get his personal stuff together I'll be out of here a little quicker and she said, "oh I've got things to do" and walked away. So I felt really rushed that one time and you know I kind of threw everything on my grandpa's lap and said, "well I guess we've got to go". I wasn't complaining but it would have been nice to have a little bit more time to get everything, we did leave some stuff behind because it just seemed like it was an emergency. There was just the one nurse there for his discharge. I knew he needed his prescription cause we had to bring his blister pack in, they lost his prescription and so we had no medicine and they said "ok well if you go down to a doctor's..." and all this stuff "they should have one down there for him" and I said "well we handed you his three weeks supply" and we're thinking well, you know he doesn't have any more now, you know or you have it so you know for them to say we have to wait for them to make up a brand new blister pack its just .. kind of inconvenient and to have the nurse say "ok well, you know, don't worry they'll give him more pills" I'm thinking 'well that's not the point'. I'm thinking you know like it'd be nice to have his pills here and then be able just to go home because that's all he wanted to do was go home. So to have to wait

in town and, and wait for more pills that he didn't really need at the time...There was no discharge planning, I wasn't involved at all, they just kind of said "K see you later" and that was it. I kind of just thought well ok there, is there any kind of paperwork I need to bring? Does he have a doctor's appointment? Or do I make one? They just said "oh, no, no he, he can just go". I just wish I knew a little bit more when I did take him out, like how did everything go? Obviously he was discharged and he didn't make a full recovery, nobody told me anything. It was kind of like, yah he's gone no papers no nothing, and just a little baggy of his stuff. I felt like it was get him out of here and leave. It would've been nice to have discharge planning, that was probably one of the worst discharges but there were times where there was one nurse that actually explained everything." (202).

"Being discharged from the hospital was great. I was out of there after being in there for a week, it was good. It was a smooth transition. They gave me what I needed and I was gone. The people involved in my discharge were the nurses, the doctor, rehab, and the health building here on the reserve. I requested on reserve services, I made sure I had my wellness plan in place before I went in. I let them know I was going for knee surgery this date and the date I'll probably

be home. They gave me a weekend home and after that they sent someone in a van to pick me up and bring me to appointments. So it was good. Discharge planning could have been a little clearer; I did a lot of the preplanning work on setting things up. I did meet with the Aboriginal patient navigator. She's actually a good friend of mine. She met me before surgery and she said, "is there anything you need like beds or anything or anything?" I said "no I have it all in place." Know your resources is my favorite saying. I knew what I had to do and what to expect, I was really involved with the planning." (204).

"Getting out, I've never had no problem with them I think because you know they need the room I've never had no problem with being discharged. They've been really good, they get your stuff together and they give all your information that you need when you go home. What you have to do. I haven't had any complaints. I haven't been involved in the discharge planning, they just come in there and they make tell you, got, you know you want to walk out but they won't let you walk out, they got to put you in a wheelchair. Well they used to long time ago and push you to the right, to the exit. But now I see they don't really do that up there now unless you're really sick." (207).

3.2.1.6. Questions: Could you describe what an ideal hospital experience would be like for you as a patient? How would you want staff to treat you?

“At the hospital I want to be treated with respect, you know how you treat people like you would like to be treated back. When I go in, say I’m bringing my grandparents, if I’m being friendly and I’m smiling and trying to get the process moving along I would like them to be more courteous and polite. It seems like they’re like robots and they’re just plugging into the computer, I want eye contact. I’ve never ever seen any of them give us any eye contact, it was just “k go over here” and “leave” and “come back” and “go sit down” so for them to be a little bit more courteous and understanding that would be great.” (202).

“Coming from a cultural community, we say ‘close family’, well everybody on the reserve is close family. The hospital is not prepared for large gatherings and when somebody gets hurt, or sick, or is dying, everybody shows up. The hospital is not equipped to handle that. We need bigger rooms closer to ICU. We need a big meeting room on each ward because you know people are people and we express our palliative care, hospice care right then and there. We don’t hold it for two years and then deal with it. We deal with our feelings;

emotions and we help support our people right then and there. So that's why we need bigger rooms." (204).

"An ideal hospital experience would be less stress and time in admitting, not having two desks to run back and forth to. More communication with my doctor, for example, instead of letting me out on a Monday he could have let me out on Friday because those three extra days I spent in the hospital wasn't worth it. They were probably trying to keep an eye on me but still. I would like staff to treat patients a little better but you know being in an overcrowded facility they don't have time to deal with patients all the time. A lot of stuff we did on our own. I would ask for more family support, I would involve more of my family. I always involve them but for a smoother transition, and in an ideal situation, they would be involved." (204).

"As a patient, an ideal hospital visit I would say being admitted goes through smooth. They put you in your room and you're happy with whoever you're in there with. That staff treat you with respect and with courtesy. My foster parent used to always tell me to respect everybody and show courtesy to everybody and it'll all be good." (207).

3.2.1.7. Question: What role do you want to play in decisions about your health care?

“I want to be involved in decisions about my health care as much as possible.

With my grandfather at the very end we didn't really know all the information and then we found out some family members would rather have seen him in a home and they kind of made a decision that they were just going to go with those family members who didn't even have a clue, they never looked after him ever. For them to listen to those people that had never been with him, just didn't make sense.” (202).

“I want to play the number one role in making decisions about my health care. I think that's being proactive, knowing what you're getting into.” (204).

“For decisions with my healthcare, I just want somebody to be there when you need them. You know I wish we had our own clinic out here, so we don't have to go so far in. I'm way down at Parker Cove. Now that I'm getting to fifty, going towards sixty, thinking oh my god what's going to happen. Look at how far I got to go for services.” (207).

3.2.1.8. Questions: What kinds of things could the hospital be doing to meet the needs of community members? For example the hospital has a smudging room and has policy about smudging. Are there other things similar to that that the hospital can do to improve your stay?

“I think it would be good for the hospital to create position, maybe a representative, who could come out to Enderby or wherever in our community, someone who deals only with us. It would be good not to be going to see all these different people and almost sometimes of getting thrown onto other people. I hear “oh well talk to him, he knows more about that stuff...” so to have somebody say, “ok, you’re an Aboriginal person, this is what we have to offer”. I know we do have nurses here but sometimes they’re just not very sympathetic to some people and that gets frustrating. It would be good if they had somebody in the hospital that strictly dealt with Aboriginal people; somebody that we can go to with any questions we have or if we needed access to a wheelchair or something else we can go to them. That person would be able to answer all our questions.” (202).

“For Okanagan community members the hospital needs a large community room. Also a larger visiting area in the patient’s room. For rooms, women with

women and men with men, that kind of thing. It was kind of hard sharing a room with two men and another woman. I'm not living in a perfect world but you know being treated as an equal is important. Even though there were others in my room they weren't treated as equals. Their needs and wants weren't met." (204).

"To meet the needs of community members the hospital should allow traditional medicine. My grandma, she was a healer and she had her own medicine. and if she wanted to come in there and give me something she should be allowed to because that's our tradition. But I know they wouldn't allow it and now she's passed on. I've seen her heal, I know a lot of people don't believe in it but I do because I've seen it. I've seen her heal a woman I knew. She's passed on now but she had a huge cancer sore on her. I remember, I was only seven or eight. My grandma drummed and bathed her in her medicine, I used to help her pick it. Then the next morning I stayed awake with her drumming. I fell asleep and then my grandma showed me where her sore was and it was gone. Where did it go? I still remember I thought how awful it looked. If they could allow our healers to come in and help." (207).

3.2.1.9. Questions: Is there anything about the physical space in the hospital you would change?

“The room my grandfather was in was very limited, it was old and cramped and seemed like it really needed some updating. Our family is huge and we had a lot of people coming in to pay their respects. That’s when we used the Okanagan Room; they said that we could go there. Another time when we said “ok we got a lot of family coming, is it going to be ok...?” because some nurses were getting upset at how many people were coming in and they said “ok well only two people at a time”. Then we had a lot of people come in, our cousins and they were upset you know there was only supposed to be two. So for them to tell us only two people allowed to come in at a time- we couldn’t comprehend that because how can you put a limit on that? Telling people that they can’t come in when your grandpa could be gone tomorrow or that hour? It’s them not thinking how we think, you know? We don’t put limits on the people coming to our house or something like that when we got a sick one living in bed waiting to die. So because of that it was kind of hard to comprehend how they can do that. It was tough.” (202).

“There’s not enough space in the hospital, in ICU, they give a little room. You’re crammed all in there trying to sit and have a coffee and pretty much you’re knees are rubbing together. They don’t have enough waiting room or room space, especially for ICU. There’s just not enough room because when you have people coming in from out of town and they want to stay there with you, there’s not enough room. You’re only allowed maybe five people in there at a time.” (207).

3.2.2.0. Questions: Is there anything about the rules in the hospital you would change?

“They did say that we’re not allowed to hang out in the hallways and if there was going to be too many of us coming up then we should maybe wait downstairs. Where he was it was kind of a long distance and we did have some elderly people there too, so for them to say that was kind of rude I thought. Those were the only rules. They were pretty good about the hours because they knew about his illness and stuff like that so I think they kind of just overlooked that.” (202).

“I would change the hospital rule on the number of people allowed to be in the room. I would change it because being Aboriginal I don’t think you can tell anybody that “only two people can come” or “oh by the way you guys have too many family members so if you guys can go downstairs and wait that would be much appreciated”. I know there used to be waiting rooms up in there but from what I’ve seen it looks like they’ve converted them into rooms. I would like the rule about only 2 family members at a time to change. That’s the only rule I can remember that I would like to change.” (202).

“I would change the hospital rules about only allowing in immediate family members. I would allow all family in not just some. If my cousin wants to phone and see how I’m doing well let him know. Its my wishes, communication.” (204).

“At the hospital, I would change rules about visiting. You know, if somebody’s in there really sick and they tell you from eight to, two to eight only. Unless it’s your husband or you’re the mother or something like that, but I see that.” (207).

3.2.2.2.1. Questions: Is there anything else you'd like to share?

“I would also like the nurses out there who work with the band or hospital to be a bit more knowledgeable of how the hospital works- how we can access funding or for instance if we needed a lift to take my grandpa out. I heard that we never had one and then I found out that we did but you know if we had somebody out there to tell us “ok well you know we could lend you a lift”. If that’s what it takes to get your grandpa home then it would be nice to have somebody there who could say “ok well there are some of the people over there that can help you” or “these are some of the companies or organizations that will maybe be able to help you also”. So maybe being able to check with them and have something ready for us the family. They knew my grandpa was not going to live that much longer so it would have been good to have the nurses on board and more helpful when we were there.” (202).

“The hospital could bring in a patient navigator full time because there are some who don’t know that she’s there. One thing I would like to bring up pertaining to culture is that when you are being admitted to just let them know you’re Aboriginal. That means a lot, I guess with the Freedom of Information Act they can’t really disclose that all the time. Let them know that you’re

Aboriginal and then they'll let Diana know or the patient navigator. I found that really helpful, just seeing her there was great. The hospital could have more room because we're larger. We're family oriented and we need more room for the people. Also more nurses and doctors but that's on everyone's wish list. I think a health care setting with more of a hospice house feel. More outside accessibility and in some areas to look more like a home. On wards you need more space for that and it would be nice to have a big feel, a big hospital area where you can have different wards, emergency and different floors. A nice courtyard instead of sitting by the road breathing in everybody's dust.

Surroundings make people get better.” (204).

“I don't think I'd change not too much, only thing I'd like is if we had our own clinic out here. I'm not prejudice or anything; it would be good for us in the long run. We should have our own doctor's office out here, our own dentists and, our own clinic and sooner or later we'll have our own little hospital. Well that's my dream, it would help us. The hospital system is overcrowded, that's about all I can say.” (207).

3.3 General themes from all interviews

There were positive experiences noted by participants with regards to treatment received in comparison to treatment that they had expected to receive. These experiences were noted as staff identified as being attentive and responsive to needs and requests with a demonstrated effort to ensure that everything “was ok”.

For example, “When my mom passed on I thought it as just great that uh staff members had let us do smudging in the room she was in that we didn’t have to go some place else. And they respected what we wanted to do.” (155).

3.3 Survey Results Selected for Further Analysis

All of the interviews completed for Aboriginal clients accessing healthcare speak to their difficulties in accessing care either for themselves or their family members. They shared similar experiences to the stories shared in the Syilx narratives. Interviews were selected for further analysis if the participants were Syilx community members and shared stories of loss within Vernon Jubilee Hospital.

The narratives cover a variety of issues and concerns that exceed the scope of this study but were included to showcase the varied experiences amongst the Syilx community.

Chapter 4: Analysis

As stated in Chapter 1, the purpose of this thesis is to examine the role of Syilx language and culture in reinforcing the importance of health and wellness in relationship to place which diverges from western ideas of health that focus primarily on the physical being. This examination is not intended to compare/contrast two systems but provide the introduction to a dialogue between healthcare providers and Syilx community members. Introducing medical providers and researchers to Syilx concepts of health and wellness has the ability to provide constructs for care that are more inclusive, which in turn can lead to improved health outcomes and experiences within local medical systems.

With that in mind, this section explores Syilx community members experiences within Vernon Jubilee Hospital through three questions- (1) How will cultural teachings emphasize the importance of wellness in relationship to place? (2) How do these teachings juxtapose with western ideas of health? (3) How will introducing medical providers and researchers to Syilx concepts of health and wellness provide constructs for care that is more inclusive, leading to improved health outcomes and experiences within medical systems?

4.1 Overview of survey

The results analyzed in this section encompass three interviews out of a possible thirty-one interviews completed by the Cultural Safety Research team.

All interviews were recorded, transcribed, reviewed and coded. Participants were given the opportunity to review their responses. The narratives selected provide a broad range of responses and speak to a number of issues outside of the research questions. Including their responses here provides an opportunity to share their voices and contribute to the education of current and future healthcare providers and researchers.

4.2 Data Analysis

Data analysis of the interviews included detailed notes/summaries completed for all individual interviews and open coding. Questions asked during the interviews were selected to analyze how interview participants experienced care and described care received either for themselves or others. The analysis is focused on current structural elements in place that shaped experiences from Aboriginal perspectives.

From the interviews selected, the overall broad themes expressed were: that health care experiences within VJH were more often negative than positive, that positive experiences often highlighted good communication/understanding between providers

and patients, that there is a perception based on past experiences that accessing health services is difficult and overwhelming which leads to individuals waiting to access care until situations become critical, that more often you will receive poor care because staff are overworked/ stressed and do not make the time to listen/communicate

4.2.1. Research Question 1 and Narratives

The first research question considered was- how will cultural teachings emphasize the importance of wellness in relationship to place? As noted by Armstrong, Syilx traditional knowledge and values are rooted in systems and place. Knowledge is passed down through families, through language, through cultural practices and cultural protocols. This knowledge is often introduced and emphasized through our stories, both *captik^wł* and *smimáy* (2013).

The stories shared with myself spoke to current gaps within the hospital system that could be addressed through a deeper understanding of how Syilx culture and knowledge reinforce practices of wellness and how those practices are intricately tied to place and connecting to the land.

Most often shared was a need to be respected- to be respected as an individual and also as a member of a larger family unit. For that respect to be reciprocal and for it

to occur by first acknowledging the individual during the process for becoming admitted. It was noted that the process for becoming admitted to VJH is long and that individuals often felt ignored and not listened to. For example,

Narrative 207 notes that

“At the admitting desk in the hospital, it seems like you’re totally ignored, when you’re standing there and they know you’re there with something. I don’t know how many times I’ve been there and they’re just typing away totally ignoring you. Then they’ll say “oh, I’ll be with you in a minute” and you’re waiting and waiting and waiting...When they admit you, I don’t think they interact with you very good, the way it should be.” (207)

Another participant expressed a common statement requested amongst almost all interviews conducted, a need for care that is respectful-

“...common courtesy is what I’m looking for, just common respect towards myself and others or the family...just treating me with respect I’ve found I want to be treated equal. Not better than some, you know, non-Aboriginal person. I want everyone to be treated equal across the board.” (204).

Narrative 204 describes their experience getting to VJH for surgery and the difficulty in navigating the system as a disabled person-

“I live on reserve, I’m in a wheelchair and I have a disability. I brought a little bag to the hospital and I was being admitted for knee surgery. I get to the hospital, there’s construction and massive mayhem- you can’t park here, you can’t park there. So the spot we were able to park in was where the old VJH was; we parked there and immediately the staff parking attendant came up and said “you can’t park there for too long”. It was like come on give me a break, I’m unloading. There was no respect given for people with disabilities or say somebody old. There was no respect just- “get out of the way, go park up there. Drop off the person who you’re dropping off and get out of here and go park over there.” (204)

Narrative 204 identified current problems within the system where patients may not have family members to advocate for them, leading to situations where the level of care is not as attentive as it should be-

“I had a plan to go into the hospital and be out as quickly as possible. The problem I had was when the elderly woman across the bed was in pain, they would tell her to hit her morphine drip and I think she was confused because she wouldn’t hit it. She would cry and the attitude towards here was really demeaning, I found it very demeaning. I felt like, she’s a patient, give her a

little empathy. There was no empathy, like the sigh and they actually gave her heck for hitting the buzzer and calling them to deal with her pain. They didn't listen to her, they didn't help her. Finally after about two hours they were able to finally hit the drip but other than that, that was the only problem that I had.”

(204)

Some of the participants highlighted the need for better access to cultural services such as smudging and accessing traditional medicines. There was confusion amongst family members as to how and when they could request additional services. For instance, Narrative 202 noted that the family had heard of cultural services offered at the hospital but were unaware of the process for requesting or accessing these services-

“At the time there were a lot of Aboriginal people in the hospital and there were a lot of people asking about it but they didn't know how to book the room.

It would be nice to see an Aboriginal section, where you could go in and you could feel comfortable and the people would know your culture or a little bit about it and understand where we come from and what we were taught. That space, if it could be larger.” (202)

Narrative 207 highlights the need for other types of medicine to be used in hospital settings, recalling past experiences utilizing traditional medicines, the participant notes-

“To meet the needs of community members the hospital should allow traditional medicine. My grandma, she was a healer and she had her own medicine. and if she wanted to come in there and give me something she should be allowed to because that’s our tradition. But I know they wouldn’t allow it and now she’s passed on. I’ve seen her heal, I know a lot of people don’t believe in it but I do because I’ve seen it. I’ve seen her heal a woman I knew. She’s passed on now but she had a huge cancer sore on her. I remember I was only seven or eight. My grandma drummed and bathed her in her medicine; I used to help her pick it. Then the next morning I stayed awake with her drumming. I fell asleep and then my grandma showed me where her sore was and it was gone. Where did it go? I still remember I thought how awful it looked. If they could allow our healers to come in and help.”

Every narrative analyzed also spoke to the need for larger gathering spaces as culturally Syilx families follow protocols for gathering during times of sickness and/or

loss. Narrative 204 identified the need for larger spaces to be more inclusive of families during times of loss-

“With a family member of mine and our past experience at VJH I’m thinking of my aunty passing away or in the midst of passing away. There’s not enough room for large groups of Aboriginal families. There needs to be a bigger room on each floor, it was really crowded.” (204)

Narrative 204 continues to note that the small spaces and the problems that families face when visiting their loved ones in hospital as the assigned spaces cannot keep everyone together-

“The hospital could have more room because we’re larger. We’re family oriented and we need more room for the people. Also more nurses and doctors but that’s on everyone’s wish list. I think a health care setting with more of a hospice house feel. More outside accessibility and in some areas to look more like a home. On wards you need more space for that and it would be nice to have a big feel, a big hospital area where you can have different wards, emergency and different floors. A nice courtyard instead of sitting by the road breathing in everybody’s dust. Surroundings make people get better.”

4.2.2. Research Question 2 and Narratives

The second research question considered was- how do these teachings juxtapose with western ideas of health? This question considers the disjuncture between Syilx values and beliefs that comprise ideas of wellness and how those ideas of wellness are excluded from western ideas of health. This section is not intended to create a yardstick for measurement of health and wellness in the Syilx community as compared to western ideals for health but rather highlight the more obvious areas of disconnect between the two.

Community members spoke to wanting to incorporate more cultural components into their care or their family members' care and not being able to navigate the hospital system. Narrative 202 describes that cultural care was wanted and not being able to coordinate that care between the family and providers-

“My grandpa wanted cultural cure, smudging and all that stuff and the health care providers said “well you know we do have a room that is available where you could all go and that in but it’s not available right now”. That was hard to hear, that there is a room but it wasn’t available to us. “I guess they call it the Okanagan Room which we knew nothing about.” (202).

Narrative 202 speaks to the importance of family support during times that family members are preparing to leave and not being understood by healthcare professionals. Protocols within Syilx communities emphasize the need for gathering. In the community, no one is turned away from the family home. Everyone is given the opportunity to visit and pay their respects to the loved one and their family in attendance. This protocol was often referenced in the interviews with regards to the rule that limited the number of family members who could be with a family member in the room at one time. The hospital implements a visiting policy for all people accessing services which does not support the cultural needs of Syilx community members saying goodbye to their loved ones.

“The room my grandfather was in was very limited, it was old and cramped and seemed like it really needed some updating. Our family is huge and we had a lot of people coming in to pay their respects. That’s when we used the Okanagan Room; they said that we could go there. Another time when we said “ok we got a lot of family coming, is it going to be ok...?” because some nurses were getting upset at how many people were coming in and they said “ok well only two people at a time”. Then we had a lot of people come in, our cousins and they were upset you know there was only supposed to be two. So for them

to tell us only two people allowed to come in at a time- we couldn't comprehend that because how can you put a limit on that? Telling people that they can't come in when your grandpa could be gone tomorrow or that hour? It's them not thinking how we think, you know? We don't put limits on the people coming to our house or something like that when we got a sick one living in bed waiting to die. So because of that it was kind of hard to comprehend how they can do that. It was tough." (202).

Narrative 204 also speaks to the importance of creating space for families during times of loss. There are protocols within Syilx communities of gathering and coming together during the end of ones journey on earth that cannot be imposed on families through rules.

"Coming from a cultural community, we say 'close family', well everybody on the reserve is close family. The hospital is not prepared for large gatherings and when somebody gets hurt, or sick, or is dying, everybody shows up. The hospital is not equipped to handle that. We need bigger rooms closer to ICU. We need a big meeting room on each ward because you know people are people and we express our palliative care, hospice care right then and there. We don't hold it for two years and then deal with it. We deal with our feelings;

emotions and we help support our people right then and there. So that's why we need bigger rooms." (204).

Narrative 202 also describes the family unit within Syilx culture and the fluidity of roles that people assume. Within Syilx communities there are no set roles that you are assigned for life- mother, father, daughter, son, etc. These positions within the family can be taken up by anyone through a variety of circumstances and it becomes difficult to navigate when the western system acknowledges your presence as one thing when you might have lived your whole life in another role.

"It was kind of hard to explain to them that even though he's my grandpa- you know he pretty much raised me when I was a kid. It's kind of hard because I didn't think I should explain myself, well you know- "hey when I was a kid he raised me since I was 15" and you know it was just kind of hard for them to say "ok well you're a grandson so try to keep it to 5 minutes". I was like "well, ok so if I was his son would I get 10?" Hearing that rule got me kind of angry." (202).

Communication was noted as being important, Narrative 204 notes that they want communication to extend beyond the current immediate family members only rule and to include the extended family. Within Syilx communities, there are not distinctions

between the immediate and extended family. The family unit is considered as a whole and ideas of extended family members as being distant are not held.

“I would change the hospital rules about only allowing in immediate family members. I would allow all family in not just some. If my cousin wants to phone and see how I’m doing well let him know. Its my wishes, communication.” (204).

Narrative 207 adds to this and speaks to the importance of being flexible with rules and shares-

“There’s just not enough room because when you have people coming in from out of town and they want to stay there with you, there’s not enough room. You’re only allowed maybe five people in there at a time. At the hospital, I would change rules about visiting. You know, if somebody’s in there really sick and they tell you from eight to, two to eight only. Unless it’s your husband or you’re the mother or something like that, but I see that.” (207).

As noted above, communication was expressed as lacking within the hospital system.

Communication that expresses understanding and honesty. Narrative 207 speaks to the unwillingness of hospital providers to reference death-

“What I would like is to be put in a good room. But when I had open-heart surgery in Vancouver I was put in a room with an eighty year old, they’re coughing and they scared me. I had my own heart surgery but you know it’s scary, like you’re scared they’re going to die in the next room. I mean the next bed. This lady was always talking to me and then I went down to do some exercise after I come back and her bed was empty and I said hey what happened to what’s her name? Oh she got admitted. I don’t think so, if she get admitted around the same time I had my open heart surgery, and then they wouldn’t tell me that she passed away.” (207).

4.2.3. Research Question 3 and Narratives

The third question considered was- how will introducing medical providers and researchers to Syilx concepts of health and wellness provide constructs for care that is more inclusive, leading to improved health outcomes and experiences within medical systems? This question reflects on opportunities for growth and change within current systems for healthcare providers and community members accessing services.

Community members expressed a need for improved communication between providers and family members accessing services. That healthcare providers make the

time to ensure that those accessing services were completely aware of what their care plans entailed and to follow up often to answer any additional questions. Participant 202 shares-

“When we found out that he had advanced cancer and that it was all through his whole body; that was tough. We were trying to explain to him what was going on and the doctor was there saying that he had two months to live, sort of a “good luck and we’ll have someone else come in and talk to you” sort of thing. To be honest, we were all bawling our eyes out and my grandpa didn’t understand what was going on. He wanted to know- what did it mean? He said “Is I’m going...am I going to die?...The doctor had no facial expressions whatsoever, he was very blunt. I felt like he didn’t have any sympathy at all. He just kind of came in and said “You’ve got cancer, six weeks to two months to live” and that was it. I found him to be very uncaring.” (202).

With regards to improved communication, participant 202 notes that-

“It would have been nice to have more help transitioning from the hospital to the reserve and for them not have so many meetings. We had a lot of meetings and it just seemed like we talked about the same things over and over. My grandpa just wanted to go home and they’re like “oh, ok well we’ll just hold

this meeting” and there are these three of the social workers there, who I believe make sure your home is ready for the person to be moved and the whole family has to be in agreement with everything. Well the home hasn’t really changed, everything is there that he needs and yeah I might physically have to pick him up this time; its just like ok do we need another meeting? Less meetings would be nice, if they knew my grandpa wasn’t going to last long why couldn’t they have sped things along and said “ok hey, you’re willing to help out, great, that’s all we need to know. End of sitting, see you later” but they didn’t do that and that was tough. So I think less meetings are good.”

(202).

Community member 204 notes the importance of involving family in the care plan and communicating as a unit-

“An ideal hospital experience would be less stress and time in admitting, not having two desks to run back and forth to. More communication with my doctor, for example, instead of letting me out on a Monday he could have let me out on Friday because those three extra days I spent in the hospital wasn’t worth it. They were probably trying to keep an eye on me but still. I would like staff to treat patients a little better but you know being in an overcrowded

facility they don't have time to deal with patients all the time. A lot of stuff we did on our own. I would ask for more family support, I would involve more of my family. I always involve them but for a smoother transition, and in an ideal situation, they would be involved." (204).

Participants also noted that they wanted to be acknowledged and treated with respect-

"At the hospital I want to be treated with respect, you know how you treat people like you would like to be treated back. When I go in, say I'm bringing my grandparents, if I'm being friendly and I'm smiling and trying to get the process moving along I would like them to be more courteous and polite. It seems like they're like robots and they're just plugging into the computer, I want eye contact. I've never ever seen any of them give us any eye contact, it was just "k go over here" and "leave" and "come back" and "go sit down" so for them to be a little bit more courteous and understanding that would be great." (202).

Narrative 207 describes waiting at the hospital to be admitted and needing urgent care.

Being triaged and waiting to access services within the hospital system is normal, however, the situation participant 207 describes appears to show discretion on part of the provider to assess the seriousness of the individual's condition prior to admittance

which does not correspond to the seriousness of the diagnosis. There does not appear to have been a verbal exchange as 207 notes-

“That time when I had a bladder infection, it was so badly inflamed or a kidney infection and I was just delirious from it. The wait was horrendous, I’m sitting there just about dying and they wouldn’t even take me yet. I guess they didn’t think I was serious enough. Finally I was ready to pass out before they acknowledged that it was really bad. I just got dumped off there, I mean the friend that I called just dropped me there and I’m sitting there and couldn’t even admit myself. But I think they’re getting better and I can understand they’re short staffed and stressed.” (207).

There were also narratives that expressed waiting to access services and not receiving the type of care expected leading to community members accessing services multiple times before being adequately treated. Narrative 207 shares-

“I remember my brother, that’s passed on, he went in to see the doctor and they sent him home. His arm was hurting and they sent him home and said there was nothing wrong with it and then all of sudden he goes back to the hospital, they x-rayed it and here it had been broken all that time. I didn’t like that. They said they had to re-break it because it had been left too long but I

don't think my brother let them. That was one of my beefs and I figured it was due to his nationality." (207).

Also participant 207 notes-

"The last time I went in there, I had broke my ankles, they put me in the back there and they just put ice on it. I was waiting for my x-rays, that was the only time I felt totally ignored. They might have been busy but it was my own fault that I didn't go in right away because I'm so far out. I thought it was just sprained so I was putting ice on it at home. I didn't want to go in because of the wait in emergency, I've been there and the wait is long. They took me in and I find out that it was broken and here I stayed home trying to look after myself but I finally got in and they operated right away." (207).

Participant 204 shared the importance of creating larger spaces to meet family needs and also a reminder that Syilx protocols of placing women with women and men with men may be appreciated but most importantly to communicate with every person admitted to the hospital on what their needs are and how can their care reflect those unique needs.

"For Okanagan community members the hospital needs a large community room. Also a larger visiting area in the patient's room. For rooms, women with

women and men with men, that kind of thing. It was kind of hard sharing a room with two men and another woman. I'm not living in a perfect world but you know being treated as an equal is important. Even though there were others in my room they weren't treated as equals. Their needs and wants weren't met." (204).

Participant 207 adds to this-

"As a patient, an ideal hospital visit I would say being admitted goes through smooth. They put you in your room and you're happy with whoever you're in there with. That staff treat you with respect and with courtesy. My foster parent used to always tell me to respect everybody and show courtesy to everybody and it'll all be good."

4.5 Analysis of Captik[™]1.

Traditional Syilx values recognize the need to live in balance both emotionally and physically for optimal health and wellness. Living in balance requires Syilx families to place children and future generations within the center of the family unit. The center of all processes and knowledge exchange is reinforced through A healthy community exists with the knowledge that future generations will continue to live and care for the land and natural resources. Syilx communities reinforce these values and practices

through story, through *captik^{wł}*. With children at the center of all decisions that are made the focus of the decision making process comes to encompass a systems approach of rebirth and regeneration. Expectations for health and wellness are repeated through story and the lessons learned through *captik^{wł}* outcomes. The concept that we are collectively responsible for the generations that will come after and that we must prepare today for those who will come tomorrow is a traditional Syilx value that is expressed through language and *captik^{wł}*.

Disjunctures between Syilx communities and local settler communities becomes more apparent in conversations had in accessing healthcare. It is clear that when Syilx access health services they are accessing institutions built with different values and priorities. Consider the *captik^{wł}* of how fire was stolen by the animal people. This *captik^{wł}* describes the problem that the *tmix^w* face in bringing fire to the land for the ‘people to be’. *C’askʔaknaʔ* leads the animal people in gathering fire and spreading it to the land. On the way of meeting the *tmix^w* gathering to discuss this problem, *C’askʔaknaʔ* prepares himself a medicine bow and arrows from the rib of *snikłca*. It is with these tools that *C’askʔaknaʔ* helps the *tmix^w* into reaching the world of the Sky people. Together the *tmix^w* build a bridge to the spirit world. This building of the bridge to the spirit world represents that journey that is made from the world of

the living to the next life, what is beyond this one. The journey that one makes from this world to the next is done with the help of the community working together to ensure a good path is made for the family member. This is good palliative care within Syilx communities.

How fire was stolen from the sky people by the animal people¹.

In the time of the animal people, the animals gathered. Q'sapi, a long time ago, Sə́nk'lip came across C'əskʔaknaʔ who was on his way to a big gathering of animal people and they started to gamble for arrows. Sə́nk'lip said "I'll go up on that mountain and if you can hit me with your bow then I'll give you back all your arrows". C'əskʔaknaʔ, who had a sʔ'aʔcínm rib for a bow, said "yes, I can hit you from here". Sə́nk'lip left for the mountain and soon forgot that C'əskʔaknaʔ was going to shoot his arrow. As Sə́nk'lip walked along he heard a noise, wind moving, and he was soon struck dead by C'əskʔaknaʔ' s arrow. C'əskʔaknaʔ came to the place where Sə́nk'lip was laying and pulled his arrow out and continued on his way to the big gathering.

¹ There are many versions to this story, the story chosen for analysis was originally told by my great great great grandfather's brother, Billie Joseph.

Ǻ^wylǻ^w came across Səñk'lip and stepped over him and brought him back to life; this was the first time that Ǻ^wylǻ^w did that. Səñk'lip was angry at being awoken from his sleep and Ǻ^wylǻ^w told him to leave C'əskʹaknaʹ alone for he was stronger than anyone. Ǻ^wylǻ^w and Səñk'lip travelled to the gathering where the other animals were waiting for them

At the gathering C'əskʹaknaʹ shot his first arrow into the sky and it stuck, he then shot three more of his arrows, each sticking into the end of the arrow in front of it. C'əskʹaknaʹ did this with arrows from every animal until the arrows reached the ground making a bridge to the sky.

Kəkwap and mənik were partners and they went up first and were followed by Stunx and Stətəlǻ^wumǻ who were also partners. The animals reached the sky and each animal went through its own hole. They decided that Kəkwap and mənik would go first to the Sky People and see about stealing fire. Kəkwap told mənik to go first and he went behind him; Kəkwap thought that his partner smelled pretty good and he licked him up until his partner was all gone. He returned to the other animals.

Stunx and Stətəlǻ^wumǻ went next to steal fire, Stunx said to Stətəlǻ^wumǻ "I'll pretend I'm dead and float down the river to the fish trap and the Sky People

will pick me up and try to skin me”. Stunx floated down the river and the Sky People pulled him out of the water and brought him to the Chief’s house to skin him. They started to skin him and Stunx bit down on the corner of his mouth so that they could not take the hide all the way off. St’əłx^wum saw this and flew to the top of a tree and around as the Sky People took their bows to shoot him, Stunx then put his hide on again and grabbed some coals and put some under his fingernail. Stunx jumped into the water and swam downstream back to the hole in the sky with St’əłx^wum following. The animals went down the arrow ladder from the sky and C’əskʔakna? pulled out all the arrows.

Stunx laid down the stolen fire, Ki?lawna decided that it was best for sux^wap to be spread through the world and so K’əkət’əłqs and X^wanəmx^wanəm traveled through the world spreading fire. K’əkət’əłqs quickly laid the fire down in another country but X^wanəmx^wanəm took a long time to spread the fire visiting every plant and flower.

The tmix^w face the task of preparing for the arrival of the people to be by collectively gathering and discussing different ways to solve the problem of getting to the world of the Sky people. The tmix^w recognize that the survival of the ‘people to be’ rests on their ability to bring fire to the land. The process of obtaining that fire describes health

and wellness within Syilx communities. Armstrong notes, to the Syilx, “...knowledge does not belong to us; we are simply carriers of it. We use the word p?ax, which literally translated, says, “to spark so as to cause to light, as in striking a match, to mean to become mind-aware as a human.” (Cardinal & Armstrong, 1991). The fire that is brought to the land by the tmix^w representing the sparks of knowledge that is needed for survival on the land. Not only the survival of the ‘people to be’ but also the survival of all living things- all of tmix^w.

4.5.1 (1) Cultural teachings emphasize the importance of wellness in relationship to place in relation to captik^w1

Cultural teachings emphasize the importance of wellness in relationship to place and this is noted through the themes of this captik^w1. There is an importance of wellness in relation to place as shown by the need to prepare the land for the people to be. The animal people do not expect the people to be to live in the land of the sky people. They recognize that they will share the land but in order to do so they must make special preparations that will ensure the continued survival of the people to be. Living together in one place speaks to the value that wellness has to be in balance; that all members of the community must be present for wellness.

When the animal people build the bridge to the sky people's land they all work together and provide an arrow to build the road. This journey from the earth to the land of the Sky people represents the journey that is made from the physical to the spiritual and the journey that is made between those worlds. The process of building the road to the Sky people involves the voices of all the tmix^w in working together to get to the Sky world. The inclusion of all through the nʔawqnxixw (consensus) process speaks to the community value of equal voice. It is through the nʔawqnxixw process that the tmix^w collectively build the road. Every single tmix^w contributes an arrow to build the road and C'əskʔaknaʔ is the one who shoots that arrow. This work was able to be completed because C'əskʔaknaʔ had taken the time to prepare his medicine bow and arrow. This can be thought of as C'əskʔaknaʔ preparing himself spiritually to complete the work that was needed from him. The road to fire, or good health and wellness, is achieved in situating the problem from the perspective of the collective. The process of gathering the arrows from the tmix^w and shooting them each one into the end of the other represents the creation of a collective vision. In this instance, the tmix^w create their vision and plan towards obtaining fire by first working together to create the road/pathway.

4.5.2 (2) How do these teachings juxtapose with western ideas of health in relation to captik^{wł}

Syilx constructs of health and wellness value the whole, that is the emotional, the mental, the spiritual and the physical; which is at odds with Western medical models which focus primarily on the physical. Western ideas of health focus on the treatment of the individual through the removal, confinement and isolation of the individual in as short a time frame as possible. Efficiency is at the heart of Western medicine at the expense of the emotional/spiritual/mental self. This differs from Syilx constructs of health and wellness, which considers all aspects of the self- the physical, the emotional, the spiritual and the mental. Syilx constructs of health and wellness consider others ways of knowing, thinking and understanding the world.

In the captik^{wł} of how fire was stolen, the animal people seek fire. In a physical sense fire is needed for survival. In a metaphorical sense the pursuit of fire or p?ax is important for the development of the mental. It represents the pursuit of knowledge, the expansion of the human mind. The idea that there are two worlds both physical and mental that can be explored with the p?ax, or fire, that exists within a person. Within Syilx communities the journey to health and wellness is explored through the mental,

emotional and spiritual self. This is at odds with medical systems, which only consider the health of the physical self and at times mental. In the *captikʷł*, C'əskʷaknaʔ, prepares himself to do this work for the people to be by preparing himself a medicine bow and arrow and because C'əskʷaknaʔ has done the spiritual work that is required of him he is able to do the physical work that is required to build the road from the physical world to the spiritual world.

4.5.3 (3) How will introducing medical providers and researchers to Syilx concepts of health and wellness provide constructs for care that is more inclusive, leading to improved health outcomes and experiences within medical systems in relation to *captikʷł*

It is important to introduce medical providers and researchers to Syilx concepts of health and wellness so as to provide constructs for care that are more inclusive. It is hoped that these conversations will lead to improved health outcomes and experiences within medical systems. This *captikʷł* illustrates that there are different levels of health and different understandings of health. For Syilx communities, health and wellness is beyond medicating the body. The creation of a new system requires the collective voice of all as spoken to in this *captikʷł*.

Chapter 5 Conclusion Kłcpəlkstini: Resurgence of traditional Syilx Health Practices

Syilx language and culture speak to the importance of health and wellness on a community level. Syilx communities currently access health systems built on western ideas of health that focus primarily on the physical aspects of health. This is in contrast to Syilx concepts of health and wellness that reflect on the whole of an individual including emotional, physical, spiritual and mental aspects of the self. Improving Syilx health outcomes through inclusive measures can be achieved through the introduction of Syilx concepts of health and wellness to medical providers and researchers. Further, direct communication is needed to move forward collectively in improving experiences in providing and accessing care, palliative services included.

This thesis considered, (1) How will cultural teachings emphasize the importance of wellness in relationship to place? (2) How do these teachings juxtapose with western ideas of health? (3) How will introducing medical providers and researchers to Syilx concepts of health and wellness provide constructs for care that is more inclusive, leading to improved health outcomes and experiences within medical systems?

This thesis utilized a literature review of Aboriginal population access of palliative care services within Canada, individual interviews and analysis of one Syilx

captik^wl. This work was done to give voice to Syilx community members experiences in accessing care at Vernon Jubilee Hospital and also to provide context for understanding what health and wellness mean within the Syilx community. This research included interviews completed by Syilx community members that spoke to palliative experiences and/or death within VJH or local healthcare systems. This thesis includes excerpts from 3 individual interviews.

With regards to research and Aboriginal peoples and palliative care services, researchers identified three main areas of concern that create barriers for Aboriginal patients in accessing palliative services and these include (1) Undeveloped/underdeveloped medical systems (2) Lack of knowledge of local cultural practices and the importance of place and (3) Lack of adequate trainers or training opportunities in learning to provide palliative services within Aboriginal communities. All of the research reviewed spoke to the need for dialogue between Aboriginal patients and healthcare providers in creating palliative care models that included traditional cultural practices.

In terms of how cultural teachings emphasize the importance of wellness in relationship to place, the narratives shared spoke to current gaps within the hospital system that could be addressed through a deeper understanding of how Syilx culture

and knowledge reinforce practices of wellness and how those practices are intricately tied to place and connecting to the land. There is a need to feel listened to and respected. The literature indicates that there is limited research on Aboriginal cultural needs with regards to palliative care delivery. Most importantly noted is that there are relationships to place that healthcare providers can see are important but are not yet fully understood as Aboriginal palliative models are so underdeveloped. The captik^{wł} of How Fire was Stolen answers how this work may proceed, it is through the collective voices each adding to the story that will build the road.

With regards to how Syilx cultural teachings juxtapose with western ideas of health, the narratives spoke to a need to increased communication. There is a desire for the incorporation of cultural components into care that is not currently being communicated. There are different expectations for care and ongoing dialogue is required to address this area. This process has been started through this thesis and will be continued through conversations within the Syilx community on stories that have been shared the work that needs to be done collectively to move forward.

Lastly, introducing medical providers and researchers to Syilx concepts of health and wellness can provide constructs for care that is more inclusive which in turn can lead to improved health outcomes and experiences within medical systems. There

is a need for dialogue between healthcare providers and patients that involves a deeper understanding. There are requests for care that are needed and not always accommodated and educational components can assist here in developing and adding to healthcare systems different ways of knowing and being. The first step in initiating those conversations is to continue this work at the community level. This thesis acts as one of those arrows and it is through other work that a road can be built.

Overall the research presented here speaks to a desire for inclusion. Syilx community members have stories to share and are willing to share them with healthcare providers. There is a need to feel respected and heard when receiving healthcare services and this is in relation to Syilx cultural values of inclusivity. Syilx health and wellness encompasses a number of factors, it considers the whole, which is currently not addressed by Western medical systems. The creation of palliative models that speak to Syilx needs can only occur through partnership. Partnerships that improve health and wellness and create new opportunities for family involvement. Life and death within the Syilx community are expressed through good health and wellness which includes an emotional and spiritual wellnes. There is a need for community members to be able to be with their family members in end-of-life care for rituals and spiritual practices that ensure their loved one fulfills their emotional and spiritual

responsibilities. These aspects are just as important as the need for physical comfort and pain reduction therapies.

5.2 Implications for Community

This research holds many implications for community education. There are knowledge transfer opportunities and applications for community, health authorities and health professionals. The purpose of this research is to provide greater context to health and wellness within Syilx communities.

Possible interventions grounded within Syilx ways of being that can be implemented by medical systems and healthcare providers include: sincere effort to acknowledge the individual and family, show sincere respect for the individual and family, to take the time to listen and believe the individual and family, to incorporate training for staff on Syilx cultural practices and traditions and to consider changes to structures that create more patient friendly care rooms, and to revise policies and procedures to reflect Syilx and Aboriginal practices.

5.3 Conclusion

This project was limited to one community within the North Okanagan but Syilx community members live throughout the Southern Interior of British Columbia and

into Washington State. As it was limited it does not illustrate a varied response as might have been expected with a larger sample. Also the literature in terms of Aboriginal palliative care and Syilx health and wellness is limited.

For myself, this research process was the start of my journey to understanding Syilx health and wellness. It was important for me to examine these narratives and be apart of this process given my story of loss at Vernon Jubilee Hospital. I believe that there are incredible opportunities for growth and transformation within rural and remote medical systems and that those journeys can start from simple conversations. There is a need to feel heard and respected. To feel like an active participant in your healthcare.

For Syilx, the journey that is made to the end of life is done collectively. The community works together to ensure that the individuals needs are met as whole. Their physical needs, their emotional needs, their mental needs and their spiritual needs. As a collective the community helps the individual to build their road to the spirit world. It is through this work that the individual can leave in a good way. These conversations need to continue not only within the Syilx community but also with local health care providers so that new roads can be built and new members can be welcomed in to the community that we Syilx call family.

I look forward to the progression of health research in the Okanagan and in closing I add this thesis as one more part of that story. This thesis is one arrow in the bridge that is being built for the people to be.

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