INDIGENOUS WOMEN WITH HEART FAILURE IN THE INTERIOR OF BRITISH COLUMBIA: IMPLICATIONS FOR HEALTH CARE SYSTEM CHANGE

by

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Abstract

Disparities in outcomes for Indigenous women with heart failure (HF) are well documented and clearly linked to: colonization, racism, and discrimination, determinants of health, and a lack of cultural safety in Western health care. The purpose of this research was to center the voices of Indigenous women themselves to inform actions for health system change which has the potential to improve their health outcomes. By utilizing conversational methods within an Indigenous research paradigm, the unique experiences of six Indigenous women within the Interior Health region of BC were explored, providing insight into what Indigenous women need to live well with HF, challenges and barriers to their wellness, and strategies to move forward in a good way. The researcher's personal reflexive work is woven throughout to demonstrate the journey to decolonize herself and her nursing practice as a non-Indigenous settler-nurse researcher.

Keywords: Indigenous women, heart failure, Indigenous research methodology, conversational methods, cultural safety, health system change

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Chapter One

Introduction

In this introductory chapter I set the stage for how I conducted myself during my research journey. With respect for Indigenous ways of knowing and being, I ventured into this journey by firstly situating myself and why this work was, and continues to be, important to me. This is of particular significance to the methodology of the research design, given the value of relational accountability when carrying out research with Indigenous Peoples, and the role it plays in building reciprocity, rapport, and trust (Kovach, 2009; Weber Pillwax, 1999; 2001; 2004; Wilson, 2008). I use the term Indigenous throughout this paper to refer to the original Peoples of the land or territory, including First Nations, Inuit, and Métis Peoples in the Canadian context while acknowledging the desire to avoid creating a pan-Indigenous approach. For consistency, where source documents use alternative terms, I have maintained use of Indigenous.

Within this chapter I share some of my thoughts from earlier reflexive journals as I started the process of decolonizing myself and aspiring to become a settler accomplice and co-resistor: meaning I want to learn how to work within the system to speak up and against racism, and colonization to become a good partner and act in ways that will support the resistance to dominionization of Indigenous Peoples in Canada (Lamont, 2018; McFarlane & Schabus, 2017; Regan, 2010). I define and describe my intentions for the use of such terms as decolonizing and settler accomplice and co-resistor. I then move on to discuss heart failure (HF), HF among Indigenous women, and my research aims and questions.

Researcher's Voice

Let us look back for a moment on my journey so I can share with you where I am coming from. It was the summer of 2018 and I had completed two semesters as a graduate student. I was developing an increasingly critical lens on the world around me. Particularly the underlying assumptions and worldviews of health, illness, and health care that inform my professional life. While I may have contemplated questioning my own assumptions, values, and beliefs in prior graduate courses, it was not until I enrolled in an Indigenous focused course that I seriously committed to looking inward and evaluating myself. I was asked to start a journal to think about my social location and situate myself at the start of this course. My first reflexive journal entry started with acknowledging my social location and how I am privileged:

> *I am a female English settler to this beautiful land known as Turtle Island prior to contact with European settlers, and now known as Canada. I was born and raised in a large urban center in central England, with the love and support of both my parents and extended family. My family are financially secure so I have been provided every educational opportunity and thus I completed my nursing degree and fulfilled my childhood dream of being a nurse. After a few years of nursing in England I followed my heart and immigrated to Kamloops, British Columbia (BC) to be with my husband in 2005. (Journal Entry, July 2, 2018)*

Reflecting on this entry now, with a deeper understanding of how to be a good ally I introduced and situated myself with no reference to the local Indigenous Peoples. Today, I start not by articulating my privilege in such a way, as most Indigenous Peoples will likely be well aware of this without me having to say it, instead I would start from a human rights perspective respecting the First Nations, Inuit and Métis Peoples as the original Peoples of the land:

> *Weyt-kp. Zoey Bradshaw En skwest. I moved from England in 2006 and have been lucky to call Kamloops my home since then. I acknowledge that I am a guest who has the privilege of living, working and playing in the ancestral, traditional, and unceded*

> *territory of the Secwepemc people in Secwepemculew. I am a graduate student, nurse, nurse researcher, wife, and mum. (Learning circle, August 11, 2020)*

I realize I have come a long way in learning how to challenge my own beliefs and values about nursing and Indigenous Peoples from 2006, to the start of graduate school, and to now, nearing graduation.

Upon entering Canada and passing the Canadian nursing exam by studying a Canadian textbook about nursing, I was able to practice as a Registered Nurse (RN) in Canada. This textbook focused on all the practical knowledge and skills I needed to know to practice safely and care for patients in Canada. However, as far as I recall, it did not include anything about providing care to Indigenous Peoples or any reference to cultural safety. My introduction to the Indigenous Peoples of Canada came from Canadian family, friends, and coworkers when I first became a landed immigrant. I remember being confused by the use of terms such as Indians to describe the original Peoples in Canada. The city of Leicester where I spent my childhood, has a large population of people who are immigrants from India. In England I had many Indian friends and was familiar with traditional Indian customs and caring for Indian patients. The people that were being referenced to as Indians, were not Indians as I understood Indians to be. I also recall hearing the negative stereotypes associated with so called “Indians”. As a novice nurse in a new land, I was confused and not brave enough to challenge what I was hearing. I went about trying to fit into my new home.

As my nursing experience grew and I spent more time working within the Canadian health care system I found myself frustrated with many aspects of my work. I decided the only way to make a significant change was to further my academic credentials. This is where my graduate journey began. The fact that I had lived and worked in Canada for fourteen years, and was not fully aware of the atrocities experienced by Indigenous Peoples at the hands of the Canadian government until I started graduate school, highlights how strong the benevolent peacemaker myth is among Canadians (Hughes, 2018; Regan, 2010). According to Regan (2010) the benevolent peacemaker myth involves the belief our institutions, such as our health care system, function well, despite evidence that they fail to meet the needs of the Indigenous Peoples accessing them. Furthermore, Hughes, (2018) questions how the deadly cocktail mix of genocide of Indigenous Peoples in Canada maintains settler indifference and thus a denial of justice. Later in this chapter and more fully in my literature review, I demonstrate how our health care system is failing to meet the needs of Indigenous women with HF.

The work of Di Angelo (2011) on white fragility provides some reason for the ongoing strength of the benevolent peacemaker myth. Di Angelo (2011) describes the concept of white fragility as "a state in which even a minimum amount of racial stress becomes intolerable triggering defensive moves which further reinstate white racial equilibrium" (p. 56). Di Angelo's (2011) work describes whiteness and how white people are protected from racial stress because of the social environment in which we live, in addition to examining how such defensive mechanisms reinforce white privilege and hinder cultural safety, a topic I address in Chapter Two. As a nurse I see the persistence of the benevolent peace maker myth, denial of justice, and the presence of white fragility in health care practice. It appears change is occurring slowly despite documents such as the United Nations Declaration on the Rights of Indigenous Peoples ([UNDRIP], 2007) the Truth and Reconciliation Commission (TRC) Calls to Action (2015), the Calls to Justice in the National inquiry Missing and Murdered Indigenous Women and Girls (MMIWG) report, (2019) and the 24 Recommendation in the *In Plain Sight* report, (Turpel-Lafond, 2020).

The more I learned about colonization, residential schools, and the cultural genocide Indigenous Peoples experienced at the hands of European settlers and government policies, the deeper shame and guilt I felt about being a white person. While this was uncomfortable to acknowledge at first, having met other colleagues who have felt the same has helped me come to terms with these feelings. My renewed passion and enhanced understanding and awareness has become part of the reasons why I wanted to use my graduate work to advance human rights and social justice, and why I am aspiring to become a settler accomplice to put to end colonial practices that deny Indigenous Peoples rights. I use the terms accomplice and co-resistor purposefully here as it speaks to my intent. While settler ally as a term has been around for a while, some critics have argued that the use of such a term has become tokenistic (Lamont, 2018). Lamont's (2018) work describes the difference between the three most commonly used terms: ally, accomplice, and co-resistor. The term settler ally is used to describe the work of non-Indigenous people educating others about Indigenous issues. Settler accomplice takes this further and refers to those that are working within the system to challenge institutionalized racism and ongoing colonization. Settler co-resistor involves the combination of theory and practice to develop authentic partnerships and community relationships and being able to critically listen. Co-resistors are critical of their own motivations behind their actions, and learn from Indigenous Peoples who are the experts in their own history, knowledge, and beliefs (Lamont, 2018). Similarly, as co-resistor I am responsible to advance and advocate for anti-racism work in BC.

Settler accomplices and co-resistors acknowledge the TRC (2015) Calls to Action and are part of the decolonization agenda. Decolonization is defined as a "long term process involving the bureaucratic, cultural, linguistic, and psychological divesting of colonial power" (Tuhiwai Smith, 2012, p.101). Decolonization involves non-Indigenous people knowing and acknowledging the colonized history of Indigenous Peoples, the consequences of this history, and how it continues to negatively impact Indigenous Peoples. Within the context of this paper, decolonization also involves recognition of the systemic gaps in health care for Indigenous Peoples (Bourque Bearskin, 2011). Decolonization involves the recognition of inequities in social order, and its influence on determinants of health for Indigenous Peoples. It requires a naming of anti-racism to create space for Indigenous Peoples to take back power, and the reclamation of traditional ways of knowing and being, of family, community, language, and culture (McFarlane & Schabus, 2017). In the research process, decolonization involves being critical of the underlying motivation, values, and beliefs that inform the research process (Tuhiwai Smith, 2012). To decolonize and be an accomplice in the resistance of colonial domination is to always be aware of privilege, the meaning of authenticity, and the ability to be critically self-reflexive, when viewing systems of oppression. This is the reason I started this chapter by situating myself and why I continue to examine my motivations, thoughts, and beliefs and its impact upon my nursing care as noted throughout my reflexive journal.

As I strive to consistently direct my gaze on anti-oppressive and decolonizing work (Lamont, 2018; Snow, 2018) I become more aware of my fear of doing the wrong thing (Doutrich et al., 2012). I am reminded of some important teachings from Knowledge Holders and Elders within the Secwepemc Nation and the written work of, and personal communications with Indigenous scholars, that help to extinguish the fear. I have learned to always ask, in a good and respectful way, and truly listen to the answers. I am calmed by knowing that if I continue to be reflexive and open to alternatives, I will decrease the probability of causing further harm. I remember the first time I introduced myself to a Secwepemc Elder in Secwepemcstin. I was so nervous I was going to get it wrong. She was thrilled to hear her language being spoken and that

I cared enough to try. I am reminded of the wise words of my professor Darlene Sanderson to be “an eagle and not a chicken” (personal communication, July 20, 2018), can be synonymous with moving through my fear and to ask difficult questions using my critical lens to take critical action.

The seminal works of Indigenous scholars such as Kovach (2009), Tuhiwai Smith (2012), Weber-Pillwax (1999, 2001, 2004), and Wilson (2008) increased my knowledge of Indigenous worldviews as relational research methodologies. In health care the Indigenous worldview continues to be dominated by the biomedical worldview that I was so familiar with and had taken for granted in all issues related to health and illness. I have practiced as an RN at Royal Inland Hospital (RIH) for over a decade now, with most of this time spent in outpatient programs designed to support those living with chronic disease related to cardiac issues. My nursing practice has largely involved implementing chronic disease self-management (CDSM) programs based on a large body of research suggesting these programs reduce disease exacerbations and hospitalizations to subsequently improve quality of life and reduce mortality. Not too long ago I would have felt quite comfortable suggesting my nursing work was benefiting the individuals I cared for during my work day. The benevolent peacemaker myth was very much alive in me, and thus I maintained a denial of justice. Willingly, but also unknowingly, I was implementing a colonial biomedical intervention without much thought for how it may be impacting those that are marginalized in society or those who’s human rights have been violated because of a different worldview and lived experience.

As a graduate student my reading list grew rapidly, I was confronted by an overwhelming amount of literature demonstrating Indigenous Peoples experiencing higher rates of all chronic conditions and poorer outcomes, which is well documented and discussed in later sections of this chapter. This made me think about my own practice and work environment. I wondered why we did not have more Indigenous Peoples accessing the heart clinic if Indigenous Peoples have higher rates of the chronic condition. It also made me wonder why, as a society and a profession, nurses, and other citizens and health care professionals and health leaders have been unable to stop this pattern of growing inequities in Indigenous social determinants of health. More importantly I wondered what was being done to correct the situation. In my reflections of my work environment, I came to realize the moral distress I experience in implementing CDSM as a standard of practice to all patients. All too often I have spent time with patients who struggle to implement our self-care teachings due to factors far beyond their control, due to social determinants of health, and then the subsequent labelling as non-compliant and the negative consequences of this label within the healthcare system.

So, motived by a desire for social justice, I found the focus of my graduate work. I wanted to use my white privilege to position myself in support of transformational change in the health care system. With all these new learnings I continue to take steps to decolonize myself and pursue my goal of becoming a practitioner that upholds human health rights and social justice of Indigenous populations in BC. My research is carried out with the intentions of generating knowledge that redresses the health inequities that exist for Indigenous Peoples. Using my critical lens to take critical action, I wanted to know why we are not doing something different that meets the needs of Indigenous Peoples and addresses health inequity? I wanted to learn from Indigenous Peoples themselves what they need to live well with a chronic condition such as HF, and help create system change that address these needs. So now I turn to the literature to better understand these inequities, why these inequities exist, and what I can do to create meaningful change.

Heart Failure: What Is It?

HF is a highly prevalent chronic condition in all developed countries throughout the world. The Heart and Stroke Foundation ([HSF], 2016) report more than 600,000 people are living with HF in Canada, with 50,000 Canadians diagnosed annually. HF is defined as a "complex clinical syndrome in which abnormal heart function results in the clinical symptoms and signs of reduced cardiac output, with or without pulmonary and systemic congestion" (Ezekowitz et al., 2017 p. 1343). HF is a chronic condition characterized by periods of acute instability and decompensation, which requires urgent treatment. HF has had many definitions and classifications over the years. Currently, HF is divided into three categories based on ejection fraction. HF with reduced ejection fraction (HFrEF), in which the ejection fraction is equal to or less than forty percent. This is also often known as systolic HF. HFmrEF describes HF with an ejection fraction in the mid-range of forty-one to forty-nine percent. While HF with preserved ejection fraction (HFpEF) classifies HF with an ejection fraction equal to or above fifty percent, also known as diastolic HF (Ezekowitz et al., 2017). HFpEF may also include right sided HF and HF due to valvular dysfunction.

The incidence of HF is increasing due to rising rates of hypertension, an aging population, and improved medical and surgical treatment of underlying conditions that cause HF, such as myocardial infarction (HSF, 2016; Kutzleb & Reiner, 2006). Improved medical technology means a greater proportion of people are being diagnosed with HF, and improved treatment modalities have enabled people to live longer with the diagnosis (Savarese & Lund, 2017). HF is a major cause of morbidity and mortality globally and nationally, often cited as a main cause of acute care hospitalizations (HSF, 2016; Paradis et al., 2010; Savarese & Lund, 2017). It is estimated that HF costs Canadians $2.8 billion each year (HSF, 2016). The usual care of anyone diagnosed and treated for HF within the Canadian health care system follows the Canadian Cardiovascular Society (CCS) guidelines for HF management, involving the use of multiple pharmaceutical therapies, and the implementation of non-pharmacological lifestyle measures that have been studied in the general population globally and nationally through a variety of quantitative and qualitative means (Ezekowitz et al., 2017).

In support of implementing guideline based non-pharmacological lifestyle measures, the British Columbia Heart Failure Network, in partnership with the HSF, have created a “Living with HF” binder that is used throughout the province to provide education and support to patients in lay terms, using clear and consistent language by all health care professionals in facilities across BC. In their *Heart Failure 101* document (British Columbia HF Network, 2012), HF is described as an issue with the heart not pumping as well as it should. This pumping problem means the body does not get the blood, oxygen, and nutrients it needs to be able to do its work properly. This results in the signs and symptoms of HF. HF is then classified as either weak pump or stiff pump. A weak pump corresponds to what I described earlier as HFrEF and HFmrEF, where the big muscle pump at the bottom of the heart is weak, large, or floppy. A stiff pump describes HFpEF, where the heart is stiff, and cannot relax properly to be able to fill with blood. The Living with HF educational resource, alongside health care professionals, is designed to ensure patients understand what is happening in their bodies, and provides them with information about signs and symptoms, treatment options, and self-care behaviors such as daily weight monitoring, fluid and sodium restriction, exercise, stress and depression, travelling, amongst other things.

Heart Failure: Focus on Indigenous Peoples

In the 2016 Canadian Census, 4.9% of the Canadian population self-identified as Indigenous (Statistics Canada, 2017). This includes those who identify as First Nations, Inuit, or Métis as per the *Constitution of Canada*, (1982)(as cited in Minister of Justice, 2021). These labels are attached by the government and do not necessarily reflect how Indigenous Peoples themselves self-identify. First Nation is used to describe any descendants of the original inhabitants of Canada, prior to contact with European settlers. This involves a variety of Nations, with a variety of beliefs, practices, and languages. Métis is term that describes those with mixed Indigenous ancestry. While Inuit is a term used describe the Indigenous Peoples of Canada's Arctic north, Greenland, and Alaska (Indigenous Corporate Training Inc, 2020; Lamont, 2018; Indigenous Services Canada, n.d,).

The percentage of those self-identifying as Indigenous in the last Canadian census has increased by 43% over ten years. Of those identifying as Indigenous in the most recent census, 18% live in the province of BC (Statistics Canada, 2017). Health care services for the Interior region of BC where I live and practice as an RN, are provided by the Interior Health Authority (IHA). IHA is a publicly funded service available to every person residing in BC, including Indigenous Peoples. Federally funded non-insured health benefits (NIHB) programs for Indigenous Peoples are administered from Health Canada to the provinces and territories, not Indigenous communities and Nations themselves. Unique to BC, since 2013, the First Nations Health Authority (FNHA) has assumed this responsibility (FNHA, n.d) . The FNHA delivers services only to those living within communities and Nations, and to First Nations only (National Collaborating Center for Indigenous Health [NCCIH], 2019; Redvers et al., 2019). Fifty-four First Nations communities are within the service area of IHA, and Indigenous Peoples make up

7.7% of the region’s total population (IHA, 2015). This region encompasses a significant land mass and communities are geographically and culturally diverse. The seven Nations that fall within IHA boundaries include: Tsilhoqot’in, Secwepemc, Dekelh Dene, St’at’imc, Syilx, Nlaka’pamux, and Ktunaxa Nations (IHA, 2015). IHA has signed partnership agreements and Letters of Understanding with these Nations, while also having agreements to support Indigenous Peoples who live in urban settings.

In Canada, as in similar colonized countries such as Australia and New Zealand, Indigenous Peoples experience a higher burden of all chronic diseases (Kolahdooz et al., 2015; Vallesi et al., 2018). Indigenous Peoples consistently experience higher rates of risk factors associated with cardiovascular disease compared to non-Indigenous populations. As a result of this higher risk factor burden which contributes to the development of HF, Indigenous Peoples suffer higher rates of HF, and at a younger age. Indigenous Peoples are twice as likely to die from HF compared to non-Indigenous populations (Clark et al., 2015; Lyons et al., 2014; Reading, 2015; Woods et al., 2012). This inequity in HF outcomes for Indigenous Peoples is multi factorial and can be linked to three main causes: The first is the negative impacts of colonization, with the loss of traditional lands, language, and cultural practices, the assimilation and segregation experience of residential school, leading to cultural genocide of Indigenous ways of knowing (Greenwood & Lindsay, 2019). This impact of colonization also includes the effect of historical and intergenerational trauma on Indigenous Peoples’ health and wellness (Fiedeldey van-Dijk et al., 2016; Iyngkaran et al., 2013; Reading, 2015; Rogers et al., 2019). The second is poorer social determinants of health which is also directly linked to the impacts of colonization (Cameron et al., 2014; Kolahdooz et al., 2015; Vallesi et al., 2018). The third is reduced access to health care services, and services that are discriminatory and racist increasing the marginalization of Indigenous Peoples, while compounding the loss of trust in Western health care by Indigenous Peoples (Aspin et al., 2012; Braun & LaCounte, 2014; Henderson et al., 2011; Iyngkaran et al., 2013; Lyons et al., 2014; Spenceley, 2005).

Despite an overall higher burden of cardiovascular disease and specifically HF in Indigenous Peoples in Australia, Canada, and New Zealand, there remains an overwhelming lack of evidence focusing on the unique needs of Indigenous Peoples living with HF. This includes a lack of evidence as to the benefits of biomedical therapeutic interventions, both pharmacological and non-pharmacological (Iyngkaran et al., 2013; Woods et al., 2012). Yet, perhaps more importantly, there is very little literature examining the impact of Indigenous specific determinants of health and how Indigenous Peoples live with HF, how HF is understood within an Indigenous worldview, or how a HF diagnosis impacts Indigenous Peoples' ability to maintain health and wellness (Crengle et al., 2014; Jowsey et al., 2013; Woods et al., 2012). To fully understand the experience of Indigenous Peoples, especially women who are at greater risk, I looked at HF in women in the general population.

Heart Failure: Focus on Women

In Canada, women make up 51% of the general population. The HSF (2018) in their report 'Ms. Understood', highlight the inequality women experience when it comes to heart disease. Cardiovascular disease is the number one cause of mortality among women worldwide, and despite rates of cardiovascular disease reducing in the general population, this decline is slower for women compared to men (Bairey Merz et al., 2017; Scott-Storey, 2013). The HSF (2018) report that women are consistently under researched, under diagnosed, under treated, and under supported compared to men with heart disease. This issue of gender and sex-based differences has gained greater attention in recent years, and this finding is echoed in much of the academic literature (Bairey Merz et al., 2017; Dewan at el., 2019; Garcia et al., 2016; Heo et al., 2019; Pepine et al., 2020; Sun et al., 2018; Tam & Pina, 2019). The majority of health care interventions, programs, and services implemented for women are based on research derived from men (Pederson et al., 2014; Prince et al., 2018). Tam and Pina (2019) report that despite fifty percent of patients with HF being women, women only make up 30% of all cardiovascular research trials. Increasingly, researchers are finding that women experience unique health needs compared to men (Di Gacomo et al., 2015). This growing body of evidence links worse cardiovascular outcomes among women to gender-based risk factors, which I discuss further in Chapter Two (Scott-Storey, 2013).

More specifically, Indigenous women are particularly vulnerable to the higher burden of cardiovascular disease and HF given the compounding nature of being both Indigenous and women (Di Gacomo et al., 2015; Prince et al., 2018). Indigenous women are more likely than Indigenous men to experience racism and marginalization (Kandasamy & Anand, 2018; Prince et al., 2018), and often fair worse among access to socio-cultural determinants (Di Gacomo et al., 2015). Just as is the case with Indigenous Peoples in general, there is little known about how Indigenous women live with HF, how they understand and manage this condition within their own lives and worldviews, or how health care providers can improve care that better supports Indigenous women in meeting their unique needs (Kandasamy & Anand, 2018).

Research Aims and Questions

A plethora of literature exists describing the rates of cardiovascular disease and HF in Indigenous populations and the reasons for these inequities, yet very few studies have been undertaken that ask critical key questions such as: how do Indigenous women experience living with HF, what determinants affect their ability to live well with HF, and what has been the experience of Indigenous women with the currently offered standard services and programs? Much of the literature and statistics have included Indigenous men and women together, so it is difficult to know the exact extent to which HF impacts Indigenous women compared to men, and how their experience may be different. There is also a lack of research piloting alternative programs and services designed to meet the needs of Indigenous women as identified by themselves.

Given the lack of available research to inform health care practice, I aimed to contribute to the development of a body of evidence that tackles this gap in knowledge. I aimed to explore the experiences of Indigenous women who live with a HF diagnosis within the interior region of BC, who currently access available services for HF patients in the local Heart Function Clinic (HFC) that services the Thompson Cariboo Shuswap region of the IHA. Two main research questions with several sub questions below frame my overall research study:

1. What are the experiences of Indigenous women diagnosed with HF, who accessed the current services offered by IHA in the HFC?
    a. How do they manage living with HF?
    b. What determinants impact their ability to live well with HF?
    c. What has been their experience when accessing the health care system?
2. Based on their experiences and perspectives, what programs and services do Indigenous women living in the interior of BC need to live a healthy life with HF?

By identifying the experiences and perspectives of Indigenous women themselves, my research will inform health systems transformation. There is much work to be done. While beyond the scope of this research, continued work must include asking similar questions of the other communities and Nations within IHA, the province of BC, and nationally.

Additionally, work needs to be done in terms of health policy, programs, and services that address the TRC (2015) Calls to Action to reduce the gap in the health outcomes of Indigenous Peoples. This research is in alignment with current policy from the FNHA and the NCCIH, that is using the current evidence base to cite improving cardiovascular outcomes and reducing health inequities among Indigenous Peoples as priorities at the federal, provincial, and local level. The NCCIH stresses focusing efforts on determinants of health, utilizing traditional knowledge, and cultural safety (Diffey et al., 2019). Provincially the FNHA (2019) in their Summary Service Plan priorities cite wellness, cultural humility, and utilizing Indigenous perspectives of health and wellness. The IHA Aboriginal Wellness plan for 2015-2019 (IHA, 2015) similarly emphasizes health equity and cultural safety as priorities for the health authority. The findings from this research will support these priorities in the health care system. Greenwood's (2019) framework for creating health system change that is discussed in Chapter Three is used in my data analysis process and is a mechanism to return the findings to co-creators, stakeholders, and decision makers within the health system as part of our knowledge translation and knowledge mobilization strategies. The term co-creator is used here and throughout this paper to identify the women who participated and co-constructed the knowledge sharing in this research.

Chapter Summary

In summary, I have shared my early journal entries to show the reader how I began decolonizing my thinking; I defined some key terms used in discussions of decolonization, and highlighted why I chose the topic of Indigenous women living with HF as the focus of my graduate work. I then reflect on the epidemiology data available concerning HF in general and specifically HF among Indigenous women. The data presented here is used as the foundation for the literature review where I further examine the available data and reasons for disparities. I ended this chapter with my research aims and questions to gain a deeper understanding of what it means to provide quality care to Indigenous women experiencing HF.

Chapter Two

Literature Review

Discussing the issue of Indigenous women with HF is complex and multifaceted. Continuing on my journey that began in Chapter One, this literature review includes many concepts that interconnect and overlap. To provide a logical review of the current evidence, I will present this literature review in three sections. The opening section provides an overview of HF prevalence globally, nationally, and particularly of Indigenous Peoples and Indigenous women. Next, I examine the inequities in outcomes for Indigenous Peoples and Indigenous women specifically with a discussion of: colonization and its impact on the health and wellness of Indigenous Peoples, while considering the role of trauma, the Indigenous social determinants, and issues influencing access to health care for Indigenous Peoples, which includes a critique of the current treatment, services, and programs available for those living with HF. In the final section, I examine the literature that focuses on changes that address the inequities in outcomes for Indigenous women, Indigenous knowledge and ways of knowing and being, and the importance of building relationships and trust with Indigenous Peoples.

Heart Failure: A Serious Problem

HF is a highly prevalent chronic condition, increasing in frequency with many treatment options but no cure. Globally, HF is a major cause of morbidity and mortality (Paradis et al., 2010) with epidemiology data suggesting 26 million people worldwide are living with a HF diagnosis (Savarese & Lund, 2017). Canada has similar rates to other developed countries such as Australia and New Zealand, with 600,000 people living with HF, and 50,000 new diagnoses every year (HSF, 2016; Savarese & Lund, 2017). The associated cost to the treatment of HF is $1 billion per year for in-patient management alone (Lyons et al., 2014) with all-inclusive costing reaching a staggering $2.8 billion every year (HSF, 2016). The incidence of HF is increasing due to improved survival rates from underlying conditions such as myocardial infarction, and from the increased rates of risk factors for HF such as hypertension (HSF, 2016; Kutzleb & Reiner, 2006; Lyons et al., 2014). This increasing proportion of risk factors for HF is especially true for instances of HFpEF, which is more prevalent in women compared to men (Garcia et al., 2016; Kutzleb & Reiner, 2006). Improved treatment options for HF also means people are living longer with the disease, and are more likely to be doing so with other comorbidities (Savarese & Lund, 2017). This is especially true for women, who are more likely than men, to live longer with cardiovascular disease, while experiencing greater functional deficit and worse prognosis (Garcia et al., 2016; Scott-Storey, 2013; Walsh et al., 2019).

Despite reductions in mortality rates from cardiovascular disease in the general population, cardiovascular disease, which is inclusive of HF, is now the leading cause of death in Canada among Indigenous Peoples (Prince et al., 2018). Looking at the epidemiology data for HF specifically, Indigenous Peoples experience a higher burden of disease, at a younger age, and are twice as likely to die from HF in the first year after diagnosis compared to non-Indigenous people (Prince et al., 2018; Thompson et al., 2016). In addition, Indigenous Peoples are more likely to live rurally, have multiple comorbidities, and are less likely to access health care services (Clark et al., 2015; Lyons et al., 2014; Reading, 2015; Thompson et al., 2016; Woods et al., 2012). However, statistics and data do not tell us everything and without the accurate data collection of Indigenous populations the inequities continue.

Heart Failure: Trouble for Women

It has been well documented that women experience poorer health outcomes compared to men, and that most health care policy and services are developed from research that largely involved men, ignoring issues that are of importance to women (Thorne & Varcoe, 1998). Evidence supports this to be the case for women living with HF. Women's hearts are physiologically different compared to men, and are impacted by hormonal changes throughout the life course (Bairey Merz et al., 2017; Beale et al., 2018; DeBellis et al., 2020; Kandasamy & Anand, 2018). Peripartum HF is only found in women, while Takatsubo and toxin induced HF due to chemotherapy treatment for breast cancer are more prevalent in women compared to men (DeBellis et al., 2020; Garcia et al., 2016).

Women experience risk factors for cardiovascular disease differently than men, and report the signs and symptoms of heart disease differently, experiencing less typical symptoms which delays access to treatment and subsequently impacts prognosis (Garcia et al., 2016; Gujral & Sawatsky, 2017). Women tend to report worse quality of life when living with HF, and experience more depressive symptoms (Garcia et al., 2016; Heo et al., 2019; Walsh et al., 2019). Consideration of gendered impacts on health and well-being in the field of cardiovascular disease has led to a growing body of evidence linking abuse as a gendered risk factor for cardiovascular disease to the higher rates of disease reported among women (O'Neil et al., 2018; Scott-Storey, 2013).

Women suffer greater socioeconomic disadvantage then men and assume a greater role in family responsibilities (O'Neil et al., 2018; Walsh et al., 2019; Ziabakhsh et al, 2016). Social and financial barriers impact access to health care and performing healthy behaviors (HSF, 2018; Kandasamy & Anand, 2018). As informal care givers for children and aging parents, women cope and manage illness differently (Di Gacomo et al., 2015; O'Neil et al., 2018). There is limited evidence about how social determinants and sociocultural factors affect women's response to health and illness, particularly when dealing with chronic conditions (DiGiacomo et al., 2015).

When living with HF, women are more likely to report a greater symptom burden than men (DeBellis et al., 2020; Heo et al., 2019). Lee and colleagues (2009) report a greater proportion of women reporting New York Heart Association class three or greater shortness of breath, compared to men who generally report class one or two shortness of breath. In 2011, Azad et al. conducted a systematic review of gender differences in HF, concluding that information on gender differences in HF is inconsistent and limited. Recent attention to gender differences in HF has led to the development of a body of knowledge that consistently reports women with HF tended to be older, have hypertension, have HFpEF, and report more symptoms and more comorbidities than men (Heo et al., 2019; Pepine et al., 2020; Sun et al., 2018; Walsh et al., 2019). Other systematic reviews have demonstrated the lack of female specific data. Much of the HF research focuses on HFrEF, and given that women are more likely to experience HFpEF, this is likely why they are under-represented in the majority of HF research (Pepine et al., 2020; Prince et al., 2017). Women who are particularly vulnerable to poor outcomes from HF are the elderly, those with social disadvantage, and Indigenous women (Kandasamy & Anand, 2018).

Double Trouble for Indigenous Women

Indigenous women face greater health inequities than non-Indigenous women. It is reported that Indigenous women have a 53% higher death rate from heart disease than non-Indigenous women (HSF, 2018; Walker et al., 2013). Indigenous women are more likely to die at a younger age than non-Indigenous women (Prince et al., 2018). The inequity in outcomes among Indigenous women is linked to: an increased rate of associated risk factors, difficulties accessing services, faring worse in all aspects of social determinants, higher rates of violence, the impact of trauma (personal, historical, and intergenerational) and high stress environments, colonization's devastating effect on traditional gender roles, and higher rates of systemic inequity and racism (Clark, 2016; Di Gacomo et al., 2015; Kandasamy & Anand, 2018; McFarlane & Schabus, 2017; Olsen, 2017; Prince et al., 2018; Smiley, 2016).

The available evidence concerning heart health and Indigenous women is lacking (Huffman & Galloway, 2010; Smylie & Firestone, 2015). Many Indigenous communities are remote, presenting logistical challenges to developing research (Prince et al., 2018). Much of the research that has been done is conducted by non-Indigenous researchers with no incorporation of Indigenous lived experiences and lacks patient oriented information and worldviews (Prince et al., 2018). This appraisal of the literature reveals very few studies focusing on cardiovascular disease in Indigenous women (Heo et al., 2019; Huffman & Galloway, 2010; Pepine et al., 2020). The lack of evidence means programs and services for Indigenous women are based on data from non-Indigenous populations which only exacerbates health inequities (Kendall & Barnett, 2015).

Indigenous Health Inequity

The inequity in health and wellness of Indigenous Peoples compared to non-Indigenous people is linked to the devastating impact of colonization and systemic racism (Downey, 2020; Stout, 2012; Stout et al., 2021). Exposure to disease and the forced assimilation via the residential school experience led to a cultural genocide of Indigenous Peoples (Partridge, 2010; Starblanket, 2018). Such genocidal acts negatively impacted traditional Indigenous culture and language, the use of traditional lands and territories, and traditional ways of life, including traditional healing and medicine practices. Colonization for Indigenous Peoples has led to: an increasingly sedentary lifestyle, a change from traditional foods to more processed Western foods, increasing food insecurity, spiritual, emotional, and mental disconnectedness, discrimination and racism, and socioeconomic disadvantage, all of which converge to contribute to the poor outcomes we are seeing in the literature for Indigenous Peoples (Campbell et al., 2007; Kolahdooz et al., 2015; Partridge, 2010; Phillips-Beck et al., 2021; Reading, 2015; Reilly et al., 2008; Tobe et al., 2015).

Prior to European contact, Indigenous communities were matriarchal and cooperative. To be able to take control of lands, colonizers removed the role and power of women in Indigenous communities and the effects of this are visible today with the shocking rates of violence against Indigenous women (Clark, 2016; McFarlane & Schabus, 2017). The change in gender roles, cultural genocide and intergenerational consequences of the residential school experience can be linked to the higher burden of risk factors for cardiovascular disease among Indigenous Peoples, particularly women (Reilly et al., 2008). With gender-based violence, racism, and discrimination increasingly being linked to chronic stress and trauma (Jackson et al., 2013; Scott-Storey, 2013).

Chronic activation of the physiological stress response has many negative consequences that impact heart rate and blood pressure leading to left ventricular hypertrophy and subsequently HF, as well as endothelial dysfunction linked to myocardial infarction (Beale et al., 2018; DeBellis et al., 2020). Chronic stress is linked to depression and impacts health behaviors linked to cardiovascular disease such as smoking and over eating (O'Neil et al., 2018). Psychosocial stress in not only linked to risk for cardiovascular disease, but also to self-efficacy, and sense of control which are cited as determinants to self-managing health and illness (Reilly et al., 2008).

There is growing awareness around violence, trauma, and the impact of trauma on health and wellness (National inquiry MMIWG, 2019), and in this case, how trauma impacts cardiovascular disease (Purkey, et al., 2018). The notion of trauma and how it relates to disproportionately worse outcomes for Indigenous Peoples was first discussed in the mental health literature in the early 1990s, focusing on historical trauma and subsequent intergenerational effects, due to colonization (Gone et al., 2019). Individual responses to trauma are impacted by a variety of factors, so supporting those living with trauma is complex (Unick et al., 2019). Much of the literature around trauma suggests Trauma-Informed Care (TIC) as a recommended approach for supporting those living with the impacts of trauma. TIC is defined as:

> ways in which violence, victimization, and other traumatic experiences may have impacted the lives of the individuals involved and to apply that understanding to the design of systems and the provision of services so they accommodate trauma survivors' needs and are consonant with healing and recovery. (Carello & Butler, 2015, p. 264)

Approaches to TIC have six principles: safety, trustworthiness and transparency, peer support, collaboration, empowerment, and being responsive to cultural and gender needs (Bent-Goodley, 2018). Based on my work experience and review of the literature, I suggest that services which address trauma and provide TIC are not reaching into the realms of supporting those living with cardiovascular disease, where the primary focus of health care interventions ignores the holistic aspect of individuals entirely. A detriment to people accessing chronic disease programs and services.

Determinants of Health

Moving on from how colonization is linked to cultural genocide and trauma, I consider the negative impact colonization has on access to social determinants of health experienced by Indigenous Peoples. Social determinants of health are the conditions in which people are born, live, and work, and that influence the health of individuals and communities (Raphael, 2009). Such conditions are inclusive of factors impacting living conditions such as housing, income, employment, food security, and working conditions. Social determinants are increasingly being incorporated into discussions concerning health and wellness as opposed to the traditional biomedical approach as they play a critical role both in the likelihood of developing a chronic disease and the ability to live well with the condition (Cockerham et al., 2017; Kolahdooz et al., 2015). Underlying political and economic factors are responsible for the inequitable access to social determinants experienced throughout society (Cox & Taua, 2017; Raphael, 2009).

Historically, discussions on the social determinants focus on healthy behaviors and on socioeconomic factors such as education, employment, income, and housing (Cameron et al., 2014). Indigenous Peoples and women often fair worse in access to social determinants due to higher rates of social exclusion that leads to lower incomes, substandard housing, and greater issues with food insecurity, all of which contribute to poor health (Galabuzi, 2009; Raphael, 2009). Focusing largely on socioeconomic based determinants can be detrimental because in doing so determinants are clumped together. Clumping determinants together leads to individual determinants not being given as much weight, or completely ignores factors which are known to impact health, such as culture and gender identities (Cameron et al., 2014; Greenwood et al., 2015). Conditions that most negatively impact the health of women and Indigenous Peoples are often ignored, especially the distal determinants such as colonization, racism, and access to health care (Allan & Smylie, 2015; Greenwood & Lindsay, 2019; Jones et al., 2019; Smylie, 2009).

To overcome the shortcomings of traditional social determinant models, an Indigenous determinants of health model has been developed to be inclusive of the negative effects of colonization, intergenerational trauma, loss of land and traditional knowledge, and racism and marginalization (Greenwood et al., 2015; Kolahdooz et al., 2015; Vallesi et al., 2018; Webkamigad et al., 2020). Indigenous determinants of health can be separated into three levels which are all impacted by and impact each other: proximal, intermediate, and distal (Loppie Reading & Wein, 2009). Proximal determinants are the easiest to see and directly affect health, including education, employment, income, housing, health behaviors, and food security. Intermediate determinants impact the environment of individuals and include the education and health care systems, medicine, kinship ties, community connection, land, language, and ways of knowing. Distal determinants are the hardest to see but have a significant impact on people's lives. Distal determinants are linked to the social, political, and historical context of intermediate and proximal determinants, to include colonization, racism and marginalization, and access or lack thereof, to health care services (Cameron et al., 2014). Racism is linked to worse cardiovascular outcomes because it is in itself a social determinant, and relates to the impact of chronic stress and trauma, both of which are barriers in accessing services (Jackson et al., 2013).

Culture as a Determinant

Indigenous determinants of health, and worldviews of health and wellness are linked to culture (Liaw et al., 2011). To be able to consider culture as a determinant we need to examine the definition of culture. Culture is difficult to define, changes over time, and is influenced by history, politics, and economics (Browne & Varcoe, 2006; Fiedeldey van-Dijk et al., 2016; Greenwood et al., 2017). The Western definition of culture is narrow as it sees cultural beliefs and values to be unchanged over time (Browne & Varcoe, 2006; Doutrich et al., 2012). Such a conception fails to account for varied levels of engagement with cultural practices and beliefs (Browne & Varcoe, 2006; Doutrich et al., 2012), or that individuals may identify as belonging to more than one culture at the same time (Cox & Taua, 2017). The Western definition fails to incorporate the impacts of colonialism and racism into its definition, and favors the notion of multiculturalism which continues to view different cultures from a dominant Western perspective. Uncritical Western conceptions and the emphasis on principles such as tolerance and acceptance ultimately reinforce privileging of the dominant culture, serving to support white fragility and leading to othering, stereotyping, and disempowerment of non-dominant cultures (Bourque Bearskin, 2011; Brascoupé & Waters, 2009; Browne & Varcoe, 2006).

Bourque Bearskin (2011) provides a definition of culture, stating “Culture is everything about people; the way they live, the way they view things, the way they communicate…. culture shapes experiences, decisions and how they relate to others” (p. 551). Critical conceptualizations of culture underpin approaches to cultural safety (Browne & Varcoe, 2006). The concept of cultural safety originated from the work of Maori scholar Irihapeti Ramsden, with the New Zealand Nursing Council incorporating cultural safety training into the requirement of nursing and midwifery education in 1992. At that time cultural safety was defined as “The effective nursing of a person/family from another culture by a nurse who has undertaken a process of reflection on own cultural identity and recognizes the impact of the nurses’ culture on own nursing practice” (Papps & Ramsden, 1996, p. 491). Cultural safety concerns the recognition of, and respect for, difference among people, while addressing power relationships between nurses and other health care providers with those receiving care, so to create a health care interaction and environment in which those accessing care feel safe to take full advantage of the services offered (Papps & Ramsden, 1996).

Achieving cultural safety is complicated due to the variety of definitions and terms. Some authors have suggested viewing the definitions across a spectrum, ranging from cultural awareness, to sensitivity, to competence, and then safety (Cox & Taua, 2017; Tremblay et al., 2019). In such a view, at a basic level cultural awareness increases one's understanding of other cultures but does nothing to change behaviors (Cox & Taua, 2017). Cultural competence moves this a step forward and involves respecting differences and accepting that people view the world differently (Bourque Bearskin, 2011). Yet, some argue against use of this term as competence implies an end result of being competent which is difficult to achieve, and pays little attention to the relationships between health care professionals and those receiving care (Cox & Taua, 2017; Curtis et al., 2019). Curtis et al. (2019) suggests that a lack of "cultural awareness" on the part of health care providers is not the issue, rather, the focus needs to be on biases, marginalization, racism, and the inequitable distribution of power and access to social determinants. Cultural safety allows for the examination of such factors, taking cultural competence further by involving consideration of the social, economic, and political position of groups. By considering historical, political and structural factors, health care professionals move beyond simply thinking of someone's cultural characteristics but instead, start to ask questions about inequities, racism, and discrimination (Cameron et al., 2014).

To promote ethical care by providing culturally safe practice and services, nurses need a more critical understanding of culture, which includes the underlying assumptions of their own culture and how the culture of others influences their ability to care for patients (Kendall & Barnett, 2015). A deeper and more critical understanding of culture also requires consideration of the professional socialization of nursing (Cox & Taua, 2017). Cultural safety provides space to enable self-reflection, engagement, and the development of mutual respect (Browne & Varcoe, 2006), while balancing power, focusing nurses on social justice, and enabling a whole-person perspective (Bourque Bearskin, 2011; Doutrich et al., 2012).

In more recent publications, the FNHA (2016) extends cultural safety to include the term cultural humility. The FNHA (2016) describe cultural safety as involving respectful relationship building, the acknowledgement of differences, and an understanding of health and wellness for Indigenous Peoples. Such a view of cultural safety ultimately balances power differentials in health care interactions to improve services and access to services that subsequently improves outcomes as mentioned above. Cultural humility involves all the aspects of cultural safety with the addition of being critically self-reflexive to understand our own biases, and being a life-long learner in the process. Culturally safe experiences can improve communication and trust within the health care system which has positive effects on access to services, enhancing cultural safety within the whole system, and ultimately the health of Indigenous Peoples (Henderson et al., 2011). For health care interactions, programs, or services to be deemed culturally safe, those accessing programs, services and receiving care must define it as such (Davy et al., 2016; Greenwood et al., 2017).

Gender as a Determinant

Gender is another critical determinant of health (Gelb et al., 2011; O'Neil et al., 2018). Gender influences all aspects of life and is particularly relevant to discussions of Indigenous health and wellness given the negative impact of colonization on gender roles and the rates of violence against Indigenous women as previously mentioned. Indigenous women face double inequity as it is reported that Indigenous Peoples and women fair worse in access to social determinants, particularly income, which has been cited as the prime determinant of health (Raphael, 2009).

Gender, like culture, is hard to define. Gender is a multifaceted social phenomenon that changes with time and culture to be reflective of what is considered masculine and feminine in a given society at a given time (Pederson et al., 2014). Gender differentiates what society ascribes as either masculine or feminine in terms of roles, behaviors, values, and beliefs (Scott-Storey, 2013). There is individual variability in how gender is expressed but this in entrenched in each society's beliefs about gender (O'Neil et al., 2018). The terms sex and gender are often used interchangeably which further adds to confusion (O'Neil et al., 2018). Sex is defined as the biological difference between men and women (Armstrong, 2009). Gender is a relational concept and linked to power. Differentiating between sex and gender however can be problematic as it implies that biological and social factors are separate, and that biology is stagnant, unchanging, and even irrelevant (Armstrong, 2009; Gelb et al., 2011; O'Neil et al., 2018; Pederson et al., 2014). Gendered transformative health promotional activities are highly important for women as they aim to address both the health of women while also addressing power inequities (Pederson et al., 2014; Diffey et al., 2019; Ziabakhsh et al., 2016).

Health Care System Impact

Access to health care has been identified as a determinant of health for Indigenous Peoples and is linked to colonization (Cameron et al., 2014; NCCIH, 2019). Historically, access to health care has been analyzed from a biomedical lens. The problem with utilizing a biomedical lens to examine and overcome access challenges is that such a lens views access to health care issues at an individual level, primarily focusing on the physical availability of services. Analysis from a biomedical lens is also problematic because it privileges the use of quantitative data which ignores the contextual realities of access issues that are relevant to Indigenous Peoples (Davy et al., 2016). Alternatively, a postcolonial lens looks at the bigger picture to consider the social, political, and historical factors that impact access to health care and would be more appropriate (Horrill et al., 2018). When analyzing access to health care, there must be consideration given to how health care is funded, and the impact of government enforced labels of “status” and “non status” to Indigenous Peoples, impacting which services Indigenous Peoples may have access to, and where they access services, contributing to inequity while also causing a divide among Indigenous Peoples (Foster, 2006; Halseth & Murdock, 2020).

Predominantly biomedical beliefs and practices throughout the Canadian health care system make health care culturally unsafe for Indigenous Peoples (Howell et al., 2016; Phillips-Beck et al., 2020). Colonial communication styles are abrupt, with a lot of questioning and the use of medical jargon (Aspin et al., 2012; Howell et al., 2016; Kendall & Barnett, 2015). Cultural and language differences can lead to miscommunication, with inadequate explanations and patients subsequently feeling misunderstood (Foster, 2006). In addition, Indigenous Peoples often have negative attitudes about Westernized health care based on prior experiences of discrimination, racism, and stigma (Aspin et al., 2012; Henderson et al., 2011; Lyons et al., 2014). Power imbalances, culturally inappropriate services, and previous experiences of racism and discrimination have led to Indigenous Peoples losing trust in the services offered and subsequently creates a barrier for Indigenous Peoples accessing services (Aspin et al., 2012; Brascoupé & Waters, 2009; Iyngkaran et al., 2013; Iyngkaran et al., 2014; Jackson et al., 2013; Spenceley, 2005; Turpel-Lafond, 2020; Woods et al., 2012). Rural and remote communities as well as urban Indigenous Peoples report challenges accessing services based on distance and transportation costs related to socioeconomic status (Syed et al., 2013).

Health care programs and services are generally designed from non-Indigenous research and non-Indigenous perspectives which can be damaging to the health and wellness of Indigenous Peoples (Nelson-Barber & Johnson, 2016; Steinhauer & Lamouche, 2015). Best practice guidelines derived from research that largely excludes Indigenous Peoples are often irrelevant for directing care for Indigenous Peoples, only further contributing to the harmful effects of colonization (Clark, 2016; Diffey et al., 2019; Iyngkaran et al., 2015; Kinchin et al., 2017). Consideration of who is commissioning, funding, and evaluating health research, and subsequently how this impacts policy and practices to further privilege Western worldviews (Kinchin et al., 2017) helps explain why the majority of health care services fail to incorporate an Indigenous perspective of health and wellness, or the role of traditional knowledge and medicines (Mbuzi et al., 2018; Redvers et al., 2019). Instead, health care services emphasize a biomedical focus on prevention, diagnostics, treatment, and the self-management philosophy that focuses on individual responsibility and management for health and illness as we shall see next (Howell et al., 2016).

Harmful Health Care Approaches

In the late 1990s, in response to the significant economic burden of managing chronic disease within acute health care facilities, the focus of care for managing many chronic diseases shifted to out-patient settings, with a focus on teaching self-management or self-care skills in addition to traditional patient education (Johnston et al., 2008). The Canadian Nurses Association ([CNA], 2012) was influential in this shift, with nurses taking a leading role implementing CDSM programs which focused on disease education while also utilizing a counselling technique known as motivational interviewing to address behavior change and increase self-efficacy (Masterson Creber et al., 2016). The goal of CDSM programs is to enable patients to problem solve and make their own health care decisions that would positively impact their health status and reduce acute care utilization (CNA, 2012; Johnston et al., 2008). However, CDSM is an example of health care approaches that are failing to meet the needs of Indigenous Peoples, including those with HF.

In the management of HF, self-care behaviors have been identified in the CCS Guidelines in recommendations 71 through 75 (Ezekowitz et al., 2017) due to large clinical trials that suggest adherence to these self-care behaviors have been linked to improved quality of life, reduced rates of hospitalization, and reduced mortality in HF patients (Clark et al., 2015; Iyngkaran et al., 2014; Riegel et al., 2016) Therefore, clinical focus continues to be placed on developing effective educational and supportive programs and services to promote HF self-care, as non-adherence is frequently associated with episodes of acute decompensation and subsequent hospitalization (Masterson Creber, et al., 2016). Yet, world-wide adherence to these recommendations is sub-optimal (Iyngkaran et al., 2014).

Privileging the focus of HF interactions with a self-care philosophy is at the cost of addressing other more influential factors in outcomes, ignoring the impact of social determinants of health in people’s ability to carry through or “adhere” to self-management education (Peters-Klimm et al., 2010). In shifting the burden of care onto individuals, the government and organizational responsibility and role in addressing the social determinants linked to health and chronic disease is ignored (Howard & Ceci, 2012). This is also true for motivational interviewing and interventions that coach coping mechanisms for stress management, placing focus on the individual and ignoring the discrimination and racism, at a societal level, creating such stress (Jackson et al., 2013).

Health care professionals are not given education to support providing self-management in a way that engages Indigenous Peoples, and tools and practices are not available in culturally safe contexts for them to be appropriate (Battersby et al., 2018). For those that believe self-care is a cornerstone of HF management, many determinants of HF self-care are identified in the literature, yet the extent to which these self-care determinants influence specific populations of patients is poorly understood and results from available studies are inconsistent (Iyngkaran et al., 2014; Materson Creber et al., 2016; Oosterom-Calo et al., 2012). Much of the research involving CDSM programs focuses on the content and impact of such interventions and not on the relationships between people, on the therapeutic relationship at the very foundation of such programs (Currie et al., 2015).

As a Western construct self-management and motivational interviewing may be harmful for Indigenous Peoples. (Ehrlich et al., 2016; Jeremy et al., 2010). CDSM programs focus on the individual which excludes Indigenous communities who value the wellbeing of the community as a whole, and who view the family, community, and Elders as highly influential in the healing process (Iyngkaran et al., 2014; Thompson et al., 2011). The notion of self-care and self-management has underlying assumptions about the roles individuals should perform in managing health and illness and the role of the health care system. Beliefs concerning illness representation and the sick role are based on cultural norms. As such, these factors could also provide a barrier to access of health care services by Indigenous Peoples (Jowsey et al., 2013; MacInnes, 2013). Written action plans are an important component of CDSM, yet Holdsworth et al. (2019) examined the use of written care plans and found them to be perceived as ineffective for Australian Indigenous Peoples, and contributing to the ambivalence Indigenous Peoples feel about the value of health assessments in their care.

Most CDSM programs have no content to account for the impact of trauma and the provision of TIC. Such standardized self-management or self-care interventions have nurses coaching patients to incorporate what has been deemed best practice into their lives. Such a practice privileges the role of the health care professional and fails to account for marginalized groups who are not represented in the studies that such recommendations have come from (Cox

& Taua, 2017; Howard & Ceci, 2012). The focus on self-management takes away from any opportunity to support people to live the life they want, or addressing the issues that are most relevant for them to live well (Davy et al., 2017). Varcoe et al. (2010) examined the use of behavior change interventions to help with tobacco use, finding them to have limited use for Indigenous Peoples, prompting the call for new models, especially practices which include Elders. Prince et al. (2018) go so far as to suggest that Indigenous women with cardiovascular disease cared for with standard biomedical behavior change and self-care measures are as manipulative, controlling, and damaging to the health of Indigenous women as residential schools.

Within health care, patient-centered care frameworks are increasingly being cited as a priority for health authorities. There is a general belief that such frameworks increase patient empowerment and quality of life as well as having a positive influence on the patient-provider relationship (Doss et al., 2011). The BC Ministry of Health (2015) patient-centered framework supports self-management and has four core principles: patient choice, which is inclusive of a patient's values and culture, information sharing, patient participation, and patient collaboration. Yet Indigenous people's values and wellness perspectives are generally not included in health care programs and services (Howell et al., 2016). The FNHA (2016) advises against the use of the terminology patient-centered, suggesting patient-centered implies a passive role by people in their care. The FNHA opt instead for the use of relationship-based care, to describe care that has people, relationships, respect and trust at the center, and which ultimately improves access to health care and other determinants of health.

Patient choice can present challenges for implementing evidence-based guidelines if the patient's choice goes against recommendations from their health care provider (Sanders et al., 2008). There may be discrepancy between the perceived goals of the health care provider for the patient and patients' goals for themselves (Zhang et al., 2015). Patients often end up "negotiating" their care due to the difference in cultural beliefs between them and health care professional (Cox & Taua, 2017). Nurses are further challenged by organizational constraints that have them juggling the many demands of the health care system and patient's needs. Patient-centered care thus requires a change in the health care professional role, seeing patients as experts in their own care (Goodman et al., 2013). Relationship-centered care that is culturally relevant, would be a step towards achieving this goal.

Generally, health care approaches are informed by evidence-based recommendations derived from large randomized trials. Yet such trials are largely representative of the dominant white culture and therefore less applicable to other groups that are not represented in these samples (Sanders et al., 2008). The review of the literature would suggest this to be the case for research on cardiovascular disease, with Indigenous Peoples being under represented (Iyngkaran et al., 2015). Those enrolled in clinical trials may fair better due to the extra attention health care participants receive when they are enrolled in research. Many Indigenous Peoples have poor access to primary care, so are certainly not receiving the same amount of medical attention as those enrolled in clinical trials (Walsh et al., 2019). Even when Indigenous Peoples are included in clinical trials, the colonial methods of measuring benefit may not be appropriate given differing beliefs of health and wellness (Angell et al., 2014; Downey, 2020). While trials focusing on women are increasing, more gender specific data is also required (Heo et al., 2019; Pepine et al., 2020; Tam & Pina, 2019).

Actions to Bridge Inequity

There is policy to guide us when considering actions that may address the health inequities documented above, globally with the UNDRIP (2007), federally in Canada with the work of the TRC (2015) and locally, both provincially and at a health authority level. Starting from a global perspective, UNDRIP (2007) has several articles of relevance. Article eleven supports the right to practice cultural traditions, and Article fifteen supports the right to dignity and diversity of culture and traditions. Article twenty-four concerns the right to traditional medicine and healing practices, and an equal right to achieve the best health possible. The TRC (2015) Calls to Action reinforces the work from the UNDRIP (2007), and clearly identifies the Federal Government's role in reducing health outcome inequities between Indigenous and non-Indigenous people. Several of the TRC (2015) Calls to Action are of relevance: Calls to Action six through twelve deal directly with addressing underlying determinants of health such as education, an issue identified here as contributing to Indigenous women's experience of living with HF. Call to Action nineteen involves closing the gap in health outcomes, number twenty-two emphasizes the value of traditional healing and the role of Elders, while number twenty-three concerns cultural competence in the health care system. Despite all this policy, and evidence clearly linking cultural barriers to poor health and the need for culturally relevant services, the development of such programs and services for Indigenous Peoples is limited (NCCIH, 2019; Prince et al., 2018; Reading, 2015).

In 2009, the Canadian heart health strategy made six recommendations for improving the heart health of Canadians. Recommendation three was concerned with the health inequities among Indigenous Peoples. This action plan stated Indigenous Peoples should have equal access to the same services as the rest of Canada. The goal was that by 2020, the burden of cardiovascular disease among Indigenous Peoples would be the same as non-Indigenous Canadians (Smith, 2009). I conclude this goal is far from being achieved.

In BC, the IHA 2015-2019 (IHA, 2015) Health and Wellness strategy for Indigenous Peoples states four strategic priorities, with health equity and cultural competency being major issues to be addressed if the health authority aims to meet the needs of the Indigenous Peoples it serves. With all this policy in place to support reducing inequities and closing the gap in health outcomes for Indigenous Peoples, there should be some evidence of improvement. I would argue that as evidenced in the literature this is not the case, and what is needed is a different approach. An approach with a stronger Indigenous presence, with more awareness, understanding, and action by non-Indigenous people as settler accomplices and co-resistors advocating for the inclusion of research by and for Indigenous Peoples. What is needed is a stronger emphasis on decolonization, Indigenous perspectives of health and wellness, Indigenous specific data collection, research, and programs, and maybe most importantly, relationship building, partnership agreements, and culturally safe relational practice training for health professionals.

Understanding Indigeneity

As previously discussed, defining culture can be difficult, and it is important to not generalize concepts to different Indigenous communities and Nations. Each Indigenous community will have its own particular beliefs and practices which should form the basis for understanding their experience and should come from the voices of Indigenous Peoples themselves (Kovach, 2009).While acknowledging my desire to avoid a pan-Indigenous approach, there are some commonalities among Indigenous communities that can be used as a starting point for further exploring the specific and unique needs of a particular communities (Fiedeldey-van Dijk et al., 2016; Iyngkaran et al., 2014). In general, an Indigenous perspective of health and wellness is holistic, and includes consideration of the spiritual, mental, emotional, and physical. Any imbalance among these four dimensions is believed to affect health and wellness (Huffman & Galloway, 2010; Marshal & Marshal, 2015). In response, the FNHA have identified their view of health and wellness which follows similar beliefs and values with some variation in throughout BC (see https://www.fnha.ca/wellness/wellness-for-first-nations).

Indigenous perspectives of health include a strong connection to the land, often seen as a determinant of health that interconnects all things (Fiedeldey-van Dijk et al., 2016; Lines et al., 2019), and is proactive with a focus on wellness as opposed to illness. The inclusion of family, the community, and Knowledge Holders/Elders are highly important, especially the role of generational knowledge transfer (Howell et al., 2016). An Indigenous interpretation of the sick role and accompanying roles and expectations also differs and may be contradictory to biomedicine's focus on favoring the individual, rather than the familial and community collective experience. Indigenous Peoples are often experiencing living with a chronic disease in between the paradigms of biomedicine and an Indigenous perspective (Jowsey, et al., 2013), with studies suggesting Indigenous communities want to see their traditional healing practices incorporated into the health care system (Howell et al., 2016; Redvers et al., 2019).

Indigenous Specific Health Data Collection, Research, and Programs

Health Data Collection. An Indigenous understanding of health differs from the Western constructs used in developing assessment tools and health indicators. Many of the available data collection methods are deficit-based measures and this can carry negative implications which further reinforce negative stereotypes and marginalization (Smylie & Firestone, 2015). Western indicators of health and illness are inappropriate for use with data concerning Indigenous Peoples, and need reinterpretation from an Indigenous perspective (Redvers et al., 2019;

Steinhauer & Lamouche, 2015). One of the barriers for policy makers and health care leaders in implementing and evaluating Indigenous specific interventions is related to challenges with collecting quality and relevant health statistics for Indigenous Peoples (Smylie & Firestone, 2015). Current data collection measures lack Indigenous identity indicators. There is a wealth of diversity among Indigenous Peoples across Canada and as such there needs to be data collected dependent on the local situational context and identified needs of each community. There is also a lack of Indigenous leaders to manage the data collected (Smylie & Firestone, 2015).

Research. As stated earlier, current health care is based on evidence generated from the general population, which is largely Caucasian. When they are included in research, Indigenous Peoples are severely under represented (Iyngkaran et al., 2015; Prince et al., 2018). If we are to address health inequities among Indigenous populations, we need research examining how Indigenous Peoples manage health and illness, and particularly how they manage their health and illness working between the two paradigms of biomedicine and traditional knowledge (Jowsey et al., 2013). Evidence of the specific HF related issues would allow healthcare providers to optimize the care they provide (Woods et al., 2012). To improve the health and wellness of Indigenous women with HF, research that analyses the impact of Indigenous determinants of health on specific communities and Nations is needed (Stout, 2015; Kolahdooz et al., 2014).

There are many similarities between Indigenous groups in Australia, Canada, and New Zealand, with a shared history of colonization, marginalization and socioeconomic disadvantage, and subsequent higher burden of chronic disease (Huffman & Galloway, 2010; Young, 2012). However, generalizations from Indigenous specific research can be challenging due to a wide diversity of beliefs and practices as documented above. People also vary in the extent to which they participate in an identified cultural group (Campbell et al., 2007; Nelson-Barber & Johnson, 2016). Therefore, research that reflects the lived experience and culture of a particular community is the most appropriate basis on which to develop initiatives and programs and services that improve wellness in those very communities (Fiedeldey van-Dijk et al., 2016). This must occur with shared responsibility between Indigenous Peoples and health care professionals if they are to build trust (Jeremy et al, 2010). Outcomes from community participatory research show greater effectiveness, but can take time to develop and measuring in quantifiable terms may be problematic (Campbell et al., 2007).

Programs and Services. Health care programs and services with a strong cultural foundation, based on evidence from a specific population with local engagement, knowledge and data collection approaches, have a greater impact on that specific population (Clark et al., 2015; Davy et al., 2016; Jeremy et al., 2013; Kendall & Barnett, 2015; Liaw et al., 2011; Mbuzi et al., 2018). Community owned initiatives enhance Indigenous empowerment and self-determination (Campbell et al., 2007; Davy et al., 2016; Huffman & Galloway, 2010). Programs and services also need to address the underlying distal social determinants of health and the mistrust in the health care system to reduce outcomes disparities (Halseth & Murdock, 2020; Thompson et al., 2016).

Huffman and Galloway's (2010) review of available programs and services found no Indigenous specific cardiovascular programs in Canada. However, I found Canadian literature of programs that have supported Indigenous Peoples living with other health and wellness concerns. For example, FORGE AHEAD is a five-year Canadian based study which developed, implemented and evaluated a culturally relevant quality improvement (QI) intervention for people with diabetes in eight Indigenous communities (Haywood et al., 2016). The QI intervention was unique to each community involved, heavily grounded in partnership with each community, having community health champions. Evidence suggests screening for and outcomes of diabetes care were improved for those involved (Haywood et al., 2020). Howell et al. (2016) used healing circles led by Elders with specific mental, physical, emotional, and spiritual components, and reported positive outcomes. Banna and Bersamin (2018) piloted a nutritional intervention bringing the community together with traditional foods, to build community collaboration.

The importance of culture in health and wellness is clearly documented and should therefore be the focus of any program or service (Kendall & Barnet, 2014). Several successful programs have been developed in Australia. Reilly (2008) found a positive influence on health and wellness for people living in traditional Indigenous communities in their heart health project. Govil et al. (2014) share the positive outcomes of the Aboriginal medical service (AMS) in rural Australia, where services are locally controlled and operated to meet the needs of that community. AMS largely involved holistic, culturally relevant services, Indigenous health care providers, and services within the community itself. These two examples from Australia provide evidence of the positive influence of traditional healing in supporting rural Indigenous Peoples.

Other successful Indigenous cardiovascular health programs in Australia and Canada, have incorporated traditional healers within the health care environment or used cultural liaison officers (Huffman & Galloway, 2010; Thompson et al., 2016). For example, an Australian study, the use of bilingual health workers and local people of the same culture showed an improvement in access to services and outcomes for some Indigenous Peoples (Henderson et al., 2011). Rix et al. (2016) another Australian study, had a staff member, the equivalent of an Aboriginal Patient Navigator (APN), employed in a hospital based renal unit where patients were receiving dialysis. The creation of this role provided support for those receiving care, but also to non-Indigenous staff in providing care, to ensure it was culturally relevant, family-centered care, that was positively viewed by patients and staff (Rix et al., 2016). Canadian studies also support the role of patient advocates, cultural liaisons, and community Elders and healers (Cameron et al., 2014; Huffman & Galloway, 2010; Varcoe et al., 2010).

Services that are relational and family and culturally centered have the greatest impact on health outcomes (Jowsey et al., 2013). The bottom line is to develop and offer heart health programs with, for, and by Indigenous Peoples (Reading, 2015). With financial support from the HSF in Canada, Reading (2015) is building on this momentum in the I-HEART program. I-HEART is the acronym for the Indigenous Health Education Access Research Training strategy. This strategy highlights the role of appropriate research that: builds capacity, impacts socioeconomics on health and disease for Indigenous Peoples, and improves access to culturally safe cardiovascular programs.

In addressing the complexities of Indigenous health, gender-based interventions for women with chronic conditions that reflect their sociocultural needs and are tailored to meet their unique necessities, may help address some of the challenges women have identified in feeling disempowered within the health care system (DiGiacomo et al., 2015; Reading, 2015). Wray (2020) shares her experience with the women's healthy heart initiative in Quebec that started in 2009. This initiative favored a nurse led rather than medical led focus to provide more holistic views of health promotion and behavior change. As a non-referral-based initiative, it enabled those without primary care providers to access its services; a constraint experienced by many in society with the severe lack of primary care. Wray further reports favorable outcomes for the women who attend, the program is still available. Another example is the Seven Sisters project carried out in BC, Canada, which was developed with a foundation of traditional healing perspectives, transcultural nursing, and feminist theory (Ziabakhsh, et al., 2016). This pilot program demonstrated how culturally relevant, women-centered, holistic supportive education programs are able to work within a biomedical and wellness focused program with Indigenous knowledge systems, to create enhanced learning and positive outcomes for Indigenous women (Ziabakhsh et al., 2016).

Relational Practice. The CDSM literature suggests the interaction of health care professional with patients is highly influential in chronic disease outcomes and potentially, such relational interactions are as important as any educational, self-care content provided during such interactions (Currie et al., 2015; Johnston et al., 2008). In prior sections it was demonstrated how relationships and trust are central to providing culturally safe care. Relationships and trust are the foundation of the therapeutic relationship, a crucial determinant in whether people access services (Spenceley, 2005). Interpersonal communication is vital to building this trust (Bell & Duffy, 2009; Pirhonen et al., 2014). We know patient-provider engagement is one of the main influencers for Indigenous Peoples in terms of choosing to access health care services, and this engagement is fundamentally linked to how culturally safe the health care provider and the environment is perceived by the person accessing care (Roe et al., 2012). Developing trusting relationships takes time and this is often an obstacle in busy health care environments. The evidence emphasizing the importance of developing interpersonal relationships for successful health interventions does not match the health care system agenda of cost effectiveness. For Indigenous Peoples, the importance of this trust cannot be overlooked as it will be foundational to developing partnerships that collaboratively develop research and programs to address the needs of Indigenous Peoples and address the TRC (2015) Calls to Action (Campbell et al., 2006; Thompson et al., 2016).

Significance

Health care professionals and health leaders need research examining the sociocultural and gender impact of living with chronic disease to inform health care policy, and direct the development and implementation of culturally and gender relevant programs and services that meet the needs of those accessing these services (Iyngkaran et al., 2014). Furthermore, health care professionals need knowledge and skills to identify individual, holistic approaches, based on the unique values of the individuals and communities being served (Clark et al., 2015; Prince et al., 2018). Gender specific research and programs and services have been shown to reduce inequity, to be empowering to women, and to subsequently improve health outcomes for women (Hoe et al., 2019; Pederson et al., 2014; Pepin et al., 2020). Culturally safe programs and services that meet the needs of future generations of Indigenous Peoples will help to narrow the gap in the incidence of chronic disease among Indigenous Peoples compared to non-Indigenous populations (Reading, 2015). Indigenous Peoples are in the best position to direct the kinds of programs and services that are most beneficial to them (Halseth & Murdock, 2020; Woods et al., 2012).

By conducting research with Indigenous women living with HF that access the current services offered by IHA, local context to the experience of the women involved is shared, and the challenges and barriers in the current services are identified, to make recommendations as to how to address these challenges if the needs of Indigenous women are to be optimally met. I found that the current evidence is lacking in terms of understanding the unique experience of women and Indigenous Peoples living with HF. This analysis on the impact of current HF services for Indigenous women in an Interior region of BC, and consideration of the needs identified by Indigenous women themselves enabled me to further explore the meaning of appropriate health service delivery as an area for further study and program development.

Chapter Summary

In bringing this chapter to an end, the literature review examined important concepts and topics related to the underlying cause of inequities in outcomes for Indigenous women living with HF. Specific strategies and the actions that address inequities at a structural, systemic, and service delivery level are a focal point. Evidence from a few countries demonstrates the vastness of need and ongoing complexities related to the health care system, gender, colonization, determinants of health, health data collection and inequities. Ultimately, in documenting the inequities, and the root causes of inequities, this provides a pathway to moving forward in a good way, and thereby highlighting the significance for this research and its findings.

Chapter Three

Methodology

Theoretical Underpinnings

A postcolonial theoretical lens was initially considered for the theoretical underpinning of this research. However, postcolonial theory has been considered problematic when implemented in an Indigenous context. In general, postcolonial theories aim to develop an understanding of the impacts of history, colonization, and unequal power dynamics on people's lives (McGibbon et al., 2014). This sounds appropriate but postcolonial theory is problematic in an Indigenous context because: it arises from a Western discourse, it separates colonizers and colonized, and presumes a shared experience of colonialism (McGibbon et al., 2014). The term post is problematic, as it suggests colonialism is over and finished. A situation I feel my literature review and many Indigenous scholars have clearly demonstrated is not the case (Bourque Bearskin et al., 2020a; Chilisa, 2012; Kovach, 2009; Kurtz et al., 2017; Tuhiwai Smith, 2012; Weber-Pillwax, 1999; 2001).

To address the inequity in health outcomes among Indigenous Peoples a different theoretical approach is required. I therefore decided to use Indigenous Research Methodology (IRM) to frame my own decolonizing methodology as the underlying theoretical foundation of my research. In this chapter I provide an overview of the decolonizing lens I used to guide my research. In addition, Greenwood's (2019) framework provides a theoretical base as a means for understanding and organizing data analysis related to action for health system change, and to guide knowledge translation. I describe Greenwood's (2019) framework in more detail later in this chapter.

Decolonizing Lens

A decolonizing approach is a useful theoretical lens used by settler allies, accomplices, and co-resistors to alter power dynamics, as a means of shifting power and decision making to Indigenous Peoples, centering both the concerns and worldviews of Indigenous Peoples, and Indigenous Peoples as full partners in reconciling historical harms (Chilisa, 2012; Kennedy et al., 2020; McFarlane & Schabus, 2017; Stein et al., 2021; Walker et al., 2013). For non-Indigenous people, decolonization is part of anti-oppressive practice in recognizing the systemic gaps in health care delivery (Bourque Bearskin, 2011; Bourque Bearskin et al., 2020b; Stein et al., 2021). Using a decolonizing lens centers Indigenous voices by placing the concerns and perspectives of Indigenous Peoples at the forefront to better understand the contextual realities from within their own lived reality (Chilisa, 2012; Simonds & Christopher, 2013; Tuhiwai Smith, 2012; Wilson, 2008). When driven by Indigenous Peoples, decolonization is about resistance to colonization and restoration of cultural practices, beliefs, and values, that have traditionally been subjugated (Canadian Association Schools of Nursing [CASN], 2020; Hughes, 2018; Jones et al., 2019). In utilizing a decolonizing lens in research, Indigenous knowledge systems and traditional teachings, such as creation stories, cosmologies, and languages, are privileged in understanding the phenomenon of interest (CASN, 2020). A decolonizing lens values the role of Knowledge Holders and Elders (Lavallee, 2009). Utilizing a decolonizing lens is empowering for Indigenous Peoples, enabling them to reclaim control and ownership over research and their own knowledge (Walker et al., 2013). The restoration of traditional rights, roles, and responsibilities of Indigenous women is also part of the decolonizing agenda (Olsen, 2017).

There is a growing body of literature incorporating decolonizing approaches into research in a positive and successful way. When discussing decolonization in the context of research, Tuhiwai Smith (2012) describes decolonization as “a process which engages with imperialism and colonialism at multiple levels. For researchers, one of those levels is concerned with having a more critical understanding of the underlying assumptions, motivations, and values which inform research practice” (p. 21). For researchers engaging in work with Indigenous Peoples, the process of critically examining one’s own assumptions and worldviews is vital if they are to be part of the decolonizing agenda. Hart (2010) talks about the complex concept of worldviews, how they develop over time and are often uncritically taken for granted. For non-Indigenous people working with Indigenous Peoples, this often involves working outside of the dominant perspective. Analyzing our own worldviews and those of the communities we serve is key if we are to do good and avoid harm in research, deconstructing the myth of the benevolent peacemaker. This requires the researcher to consider the impact of historical treatment, particularly the poor treatment Indigenous Peoples have faced in research, and the ongoing denial and negative consequences of this history, along with understanding the impact of colonization and marginalization (Hughes, 2018). This critical analysis of one’s underlying assumptions is essential to the analysis of inherent positioning and power differentials between researchers and research participants (Kovach, 2009; Simonds & Christopher, 2013).

In choosing to use a decolonizing approach I begin my research with personal reflections and reflexivity, as a way to take stock of my own values and how they influence my nursing practice. As a non-Indigenous settler, decolonization requires an exploration of how I am situated within colonialism, and how I navigate the challenges. This is documented in my reflexive journal intertwined throughout the research and discussed in more detail throughout the subsequent chapters. For example, one of my earliest entries demonstrated how even with good intentions and all the reading and awareness I thought I had, it became apparent that my worldview is deeply ingrained, and showed up without me realizing it at first. In creating a condensed conversation of the women's stories, I included my words and interpretations within the conversation, despite my goal of the condensed conversations being to privilege the words of the women themselves. In my journal I wrote:

> *Here's my white privilege showing up; that I wrote the first draft about MC rather than just telling her story with her words! I didn't even realize to begin with. This shows how deeply embedded our ways are even when trying to be decolonizing and thinking about power all the time I still did this.* (Journal entry March 10, 2020)

A Framework for Health System Change

To enhance my decolonizing approach in this research, the findings are further synthesized and translated into practice utilizing the framework for change and cultural safety as identified by Greenwood (2019). This framework is complimentary to the models of Indigenous health and wellness and Indigenous determinants of health that I have described in the literature review. The framework has three interconnected layers for achieving cultural safety and health care transformation in complex systems which allows for the "causes of the causes of the causes" (p. 13) to be addressed. The outermost circle encompasses the structural level of change for achieving cultural safety, and is inclusive of legislation and policies, such as those from the FNHA. The next inner circle involves the systemic level and direct services including services for education, health, and justice. This would also involve the impact of the FNHA, and IHA wellness plan. The innermost circle addresses the service delivery level transformation for achieving cultural safety, that is, the point of care of human interaction and individual experiences of cultural safety.

Greenwood's (2019) framework fit well within my research, as I started by exploring the service delivery level, that is the experience of Indigenous women living with HF who have accessed the HFC. The women shared their experience of current service delivery, and made recommendations about programs and services that would be more culturally safe at the service delivery level, as well as knowledge translation and mobilization approaches. The knowledge sharing and subsequent meaning making was used to suggest systemic level change in the health care system that centers Indigenous voices, and address health inequities for Indigenous women to achieve cultural safety. Identifying systemic level changes in this context served as a mechanism to bring forth new ideas and strengthen partnerships, between IHA, FNHA, communities, and Nations. The structural level of change to support cultural safety was considered as I identified the available policy, legislation, and agreements that impacted the women's experience and supported the changes the women themselves recommend.

Methodological Processes

Methodology describes the underlying strategy, plan, process, and design behind the choice of method for data collection and analysis. Throughout this research I use IRM as a decolonizing approach described by Tuhiwai Smith (2012). In this section, I briefly describe what is meant by IRM, before moving on to discuss the methodological aspects of the research. I include a discussion on recruitment, and how knowledge sharing and meaning making occurred. I share how I overcame the barriers of carrying out research during a global pandemic. I then address trustworthiness, ethics, and knowledge translation in relation to this research.

Weber- Pillwax's (1999; 2001; & 2004) work is influential in laying out the ontological, epistemological, methodological, and axiological aspects of IRM that needs to be followed by researchers working within an Indigenous research paradigm (Wilson, 2001). IRM privileges Indigenous voices, knowledge, cultural practices and protocols, and Indigenous concerns (Tuhiwai Smith, 2012). The use of IRM decolonizes research and contributes to the self-determination of Indigenous Peoples (Wilson, 2008; Wright et al., 2016). The use of IRM helps non-Indigenous people understand Indigenous worldviews (Wilson, 2008). Such understanding is a key component to decolonizing and an essential step in my journey to begin working with Indigenous women in my research.

According to leading Indigenous health researchers, (Bourque Bearskin et al., 2016; Kurtz, 2013; Kurtz et al., 2017), IRM acknowledges the holism and interconnectedness of the physical, emotional, mental, and spiritual aspects of the individual with all living things, the Earth, and the universe. IRM's key elements include a recognition of Indigenous ways of knowing and being. This involves centering the uniqueness, and the values and beliefs of the Indigenous Peoples involved in the research, particularly avoiding a pan-Indigenous approach. Furthermore, there needs to be relational and respectful practices, there must be the promotion of social justice, appropriate cultural and ethical protocol must be followed, and it must build trust. In addition, there must be adherence to the principles of collectivity and reciprocity, with community engagement and respect. Finally, it should privilege Indigenous methods that treat the collected data with respect.

Relationships and the concept of relational accountability are crucial to IRM (Wilson, 2008). Relational accountability involves conducting research in a good way, following the principles of respect, responsibility, relevance, and reciprocity (Kirkness & Barnhardt, 1991;

Kovach, 2009; Rix et al., 2014; Wilson, 2008). This is why this research project and thesis started with my own personal reflections and self-location. Given the importance of relationships to Indigenous methodology, the fact that I, as the principal researcher may have an existing relationship with the women who participated was seen as beneficial in enhancing the trust in the relationship, something which takes time to develop (Kovach, 2010). Relational accountability is important for trustworthiness and will be discussed again later in this chapter.

Reflexivity

Reflexivity is crucial to IRM, and especially for myself as a white settler, as it allows for the multiple roles of the researcher to be analyzed, as well as addressing power dynamics (Rix et al., 2014; Tuhiwai Smith, 2012; Ziabakhsh, 2015). It is my intention to weave my reflexive thoughts and journey throughout this chapter and subsequent chapters. I used my journal to work through the challenges I was having with examining myself as a researcher and nurse, trying to separate my roles as nurse and researcher, ultimately reaching the conclusion that this separation was unnecessary and that the role of nurse-researcher was beneficial to the methodology and knowledge sharing.

Reflexivity is used as a means to explore my own self-location to acknowledge the importance for both positioning one's self in establishing trust and reclamation of research partnerships (Lavallee, 2009). When I look back at my journal entries as I consider the establishment of trust in the research process, I can see the difference in my nervousness and preparation with women I knew compared to the ones I had not previously met. I acknowledged the positive impact of my first co-creator being someone I knew already when I wrote *I'm so glad my first conversation is with someone I know, the strength of relational accountability and that I hope from her experiences with me she knows I bring good intentions* (Journal entry

January 24, 2020). This compares to my journal entry of March 2, 2020 when I wrote: *MB doesn't know me so the experience will be quite different in the beginning and the need to properly situate myself is even more important.* I was more concerned I would mess things up with women I had not met in the clinic because they have no preformed idea of me. Yet, as I later reflected on this, this belief presumes the women I have provided care to see me in favorable terms, and maybe this was one of their reasons for agreeing to participate. This could be a false assumption as I am presuming that I am being effective in providing care to my patients, yet I readily acknowledge the moral dilemma my work environment triggers within me on a regular basis and the systemic factors that detrimentally impact my ability to give patients what they need. This issue with trust and relationships also became even more powerful when I had to switch the knowledge sharing mode to telephone due to the COVID 19 pandemic, as I discuss later.

Reflexivity further allows for the researcher to process and understand difficult and distressing emotions that may be incurred during the research (Doyle, 2013). One of my biggest frustrations was hearing of the poor experiences the women have faced in their health care encounters, and my disappointment in my colleagues and profession for not meeting patient's needs. I also questioned my own effectiveness in providing care when I was a nurse clinician. I found hearing the traumatic life events the women are experiencing emotionally draining, and the session where this emotional distress was most prominent, I delayed transcribing for several days after the session, whereas for the others I had started transcribing right away. Such an experience highlights how in order to protect myself as a nurse from the overwhelming nature of patients lived experiences, I may not listen deeply. Acknowledging these powerful emotions in my journal helped me move forward by accepting the idea of being comfortable with the uncomfortable.

Recruitment

Criterion sampling was used to recruit Indigenous women living with HF in the Interior region of BC that have previously, or are currently, accessing services provided by the HFC at RIH (Kovach, 2009; Wright et al., 2016). Criterion sampling involves recruiting co-creators based on a set criterion for the needs of the research, as identified in the inclusion criteria. This ensures rich and relevant data collection and makes the idea of saturation less of a concern, which is important given that the concept of saturation is not very applicable to conversational methods (Vasileiou et al., 2018). There was no need to achieve a set number of co-creators as the study goals did not involve generalizing the results in any way but to collect rich descriptions of the women's experiences. Recruitment was somewhat based on pragmatic considerations given time, expense, and manageability of this research as a graduate student (Vasileiou et al., 2018). The inclusion criteria included: women who self-identify as Indigenous, aged 18 years or older, with HF of any etiology, English speaking, and who provided informed consent.

Two recruitment strategies were used: recruitment posters (see Appendix A) and a third-party method. Recruitment posters were placed around RIH, including the HFC. The recruitment poster requested that interested co-creators contact myself for screening for inclusion and to discuss the research project further. However, ultimately all of the co-creators were recruited by third-party recruitment. Third party recruitment occurred with team members within the HFC following a set script (see Appendix B) given to them by the primary researcher. This script involved the HFC nurses asking every woman who accessed the clinic if they self-identified as Indigenous. Those who responded yes were then asked if they would be willing to be contacted by the primary researcher to discuss the research further, and signed a consent to contact form (see Appendix C) if they agreed.

During the initial recruitment phone conversation, I reviewed the research project and the consent form (see Appendix D). I advised all potential co-creators that I am both a nurse who has previously worked as the primary nurse within the HFC as well as the researcher. We discussed their preference for time frame of the data collection, and length and location of sessions, which added an element of participatory research. Six women were recruited between January 2020 and June 2020. The sample size was limited to ensure logistically everyone was able to participate in the learning circle, having the opportunity to have their voice heard and share their experience. I also set a time limit for recruitment to try to reduce the withdrawal rate, to aid in the continuity of co-creators, and to have the data collection completed in a timely manner for myself. An honorarium of $25 was provided to the women to compensate for their time and the knowledge they shared at each of the two phases of the research (Groth, 2010).

Knowledge Sharing Summary

In keeping with the principles of IRM, conversational methods were used to collect narrative data of the experience of Indigenous women living with HF. Conversational methods are a non-structured method for knowledge sharing with the option to use some open-ended questions to prompt conversation. (Kovach, 2009; 2010). Conversations and stories as a method for knowledge sharing correspond well with IRM due to a strong tradition of orality among Indigenous People's ways of knowing and being (Campbell, 2014; Kovach, 2010; Simmonds & Christopher, 2013). Utilizing conversational methods ensures data collection occurs in a culturally appropriate way, privileging the voices of the Indigenous women participating in the research. As such, these methods are relational, collaborative, and decolonizing (Kovach, 2009, 2010). Conversational methods ensure co-creators experience greater power in the research process, as they determined what they choose to share (Drawson et al., 2017; Kovach, 2009). Conversational methods also position the researcher as a participant and co-creator in the knowledge sharing process (Drawson et al., 2017; Kovach, 2010). The primary role of the researcher is that of active listener to learn from the Indigenous women sharing their story and knowledge (Kovach, 2009). I utilized two conversational methods to address my research questions. The first phase knowledge sharing occurred with one-to-one conversations between the women and myself as the primary researcher. Following adequate recruitment and initial analysis of these individual conversations I then utilized a learning circle for the second phase of knowledge sharing. The goal of the learning circle was to cultivate shared experience, discuss themes and key learnings, validate my interpretation of their experience, and enable the women to be co-constructors in meaning making and the creation of recommendations for health care system change, and knowledge mobilization strategies.

One-to-one Conversational Meetings. After obtaining informed consent, individual experiences were shared during a one-to-one conversational meeting between each woman and the researcher. Some guiding questions were developed with the support of Gwen Campbell McArthur, an Elder advisor, and the thesis committee (see Appendix E). These one-to-one conversations captured rich data of each woman’s experience of living with HF. Face-to-face was the preferred means for hearing the women’s stories, but due to the global pandemic some had to be collected by phone and I will discuss the impact of this later. One-to-one meetings lasted between 50-75 minutes, and when completed in person, occurred at a location of the woman’s choosing.

The location of knowledge sharing was an important consideration during the planning phase. The environment needed to be comfortable, neutral, accessible, and provide privacy and no distractions to ensure the women's comfort. The research setting is also important as it can impact the power dynamic of the research (Manderson et al., 2006). For this purpose, a non-hospital location was chosen. Two meetings were completed face to face in a private office space within the community. One co-creator chose to complete the meeting in her own home. Three co-creators had to have their one-to-one via the phone due to the global pandemic.

Face-to-face and phone conversations were audio recorded and then transcribed verbatim by me. Recording conversations is important as it helps ensure true representation of what was shared (Kovach, 2009). By personally transcribing the conversations I was able to ensure the knowledge shared stayed with the two of us, and working so closely with the data aided meaning making more so than if the meetings had been transcribed by a third party. By personally transcribing the conversations continuity of commitment to the co-creation of knowledge was strengthened, and re-hearing the voices was like being with the women again. These transcriptions formed the basis for both meaning making and for the creation of condensed conversations.

Learning Circle. The second conversational method I utilized was a learning circle. The learning circle in this situation was facilitated by a Knowledge Holder, Colleen Seymour, familiar with the learning circle processes. Learning circles provide all co-creators an equal opportunity to speak and be heard in a non-judgmental environment. The power of the circle neutralizes power differentials between participants and researchers (Botha, 2011; Kendall & Barnett, 2015; Wilson, 2008) The circle allows for collective decision making which is in keeping with traditional Indigenous worldviews (Kovach, 2009). Learning circles situate the researcher within the knowledge sharing process, and give control to participants over what is shared, and what is collected just as with individual conversational methods (Drawson et al., 2017). In this research, the learning circle was a way to incorporate local Indigenous protocols and provided co-creators a space to share their experience, in a culturally relevant way that also supports a joint data analysis and meaning making process. The goal of the learning circle was to create space for the women to share common experiences, to collectively make suggestions for change and creating culturally safe programs for women with HF, and to identify ways the knowledge shared could be mobilized in a good and respectful way (Drawson et al., 2017).

From my conversations with the women individually I was aware that some of them had never been to a circle and so to prepare them for what to expect I mailed an outline (see Appendix F) of how the circle would flow to help build understanding and set expectations. I also included some of the questions I had that I hoped we would discuss during the circle to allow the women to consider how they might respond to these questions before hand. These questions included: consideration of their experience, the map I had created and if I had captured their experience correctly, what kinds of programs and services they would like to see for Indigenous women with HF, with whom they would like to share the knowledge we created in this research with and how we would share this, and finally, consideration for how much they wished to be involved in knowledge translation.

In the weeks prior to the circle the women were contacted to discuss availability, time and location of the circle. An updated version of the condensed conversation was mailed to each co-creator which included deeper data analysis that had occurred since the initial creation of the condensed conversation, alongside a concept map of their experience that had been created to address the research questions. Three of the six women were able to attend the learning circle on

August 11, 2020. As HF patients are vulnerable to tiring quickly the circle was planned to last no more than two hours. This time frame included the sharing of food prior to commencing the recorded part of the circle.

During a learning circle a set protocol is followed, depending on the local context, which usually involves proceeding in a unidirectional manner, with a talking stick or stone, and may also involve smudging or other ceremonial practices (Lavallee, 2009). As introduced above, in this research, Knowledge Holder Colleen Seymour facilitated the circle and guided me in developing the agenda for our time together with the co-creators. This agenda was also reviewed with the women verbally at the start of the circle and was in a visual format which we put up on the wall. Each co-creator, including myself and Colleen were given tobacco at the start of the circle, as thanks for the knowledge about to be shared, and a further means of reaffirming their original consent before the circle started (Drawson et al., 2017; Kovach, 2009; Lavallee, 2009). Colleen began with a smudge, share water and spiritual plate of our food offerings were placed in the center of our circle, alongside her eagle feather. One of the women required continuous oxygen therapy and therefore the group decided not to burn the smudge during the circle but to have it in the center of the circle instead. Colleen then gave an opening prayer.

The first round of the circle was for introductions, and we all introduced ourselves with name and where we are from. In round two, I started by sharing what I had learnt from the women overall about the experience of living with HF, and what I had learnt about myself in this research journey. The women then shared their experiences of living with HF with each other. In round three we identified whom the women wanted to share their experiences with and how they would like to share the knowledge we were co-creating (our knowledge translation and mobilization strategies). The final round, round four, was for the women to suggest programs and services they felt they needed to meet their health and wellness needs. Colleen then closed our circle with final words and blessing and took our smudge, share water and spiritual plate to the local mountains, to return it to the Earth. The smudge burnt quickly, which Colleen advised me means the women were able to share what they needed.

The circle was audio recorded and transcribed verbatim by me for the same reasons as discussed in the one-to-one conversation section above. A condensed conversation of the circle was created and shared with the circle co-creators in the same way as had been done for the one-to-one conversations. The knowledge shared during the circle was analyzed the same way as the individual data, as I shall describe in the following section.

As the primary researcher I kept field notes alongside my reflexive journal that further informed meaning making. Reflecting on the experience of participating in the circle immediately after, I was struck with the realization of how powerful it had been for the women to come together when I wrote *how healing it was for the ladies themselves to share with each other, to share with those who experienced similar things* (Journal entry August 11, 2020). The circle in itself had provided an opportunity for the kind of support they were asking for in their suggested recommendations, and it was powerful to witness and be a part of this healing. I also used the circle to show my commitment to the women by openly discussing my own vulnerabilities, struggles, and personal learnings, such as my fear of causing harm by making errors with cultural protocol, and how difficult it was to hear their experiences of racism and discrimination, and the loss of their family members. Given how hearing of these experiences made me feel, I can only imagine the burden this must be for Indigenous Peoples living with such realities, who are not able to move away from these experiences or access appropriate mental health services to deal with this historical trauma.

Meaning Making

Following each knowledge sharing session I began by listening to the audio recording and documenting my initial thoughts, feelings, and learnings in my reflexive journal. I used this as an opportunity to highlight the main threads in each conversation, and as the number of co-creators increased, comparing their experiences to prior conversations. My initial thoughts often involved frustration and shame as a nurse at the poor care the women had received in the health care system, and sadness at some of their life experiences. Journaling these powerful emotions right away providing a way to acknowledge these feelings and move forward in a good way. Uninterrupted listening of the stories and lived experiences was important for honoring the Indigenous tradition of orality (Bourque Bearskin et al., 2020b).

Next, I transcribed the audio data verbatim. This in itself was quite the experience. Transcribing the audio personally really highlights how my own beliefs and values shape the way I hear things. Often, I would type what I thought was said by the participant, only to hear it back and realize the subtleties that I had somewhat unknowingly added to their words. The use of language became a common thread in itself, but also in my personal workings with the language the women used compared to myself. As I developed my skills in this with each subsequent transcript, I felt that my mis-hearing of the women’s words became less common, demonstrating my personal growth. Transcribing an emotional story also adds to how upsetting it is to hear that story, when it is played over and over, but I think for me it served to really build empathy of the experience, and aid in decolonizing as I was constantly thinking about my role, my beliefs and motivations and how this unknowing impacted my own practice.

Once completed this transcribed document was then replicated three times with each copy serving a different purpose; One copy included all the transcribed text, and was used to record meaning making and reflexive journaling thoughts alongside the women's words. The second and third copy of the transcription then had the researcher's words removed. This enabled a deeper focus on the co-creators' words and experience. One version was highlighted in different colors to identify threads and concepts related to the research questions. The other version was used to highlight the key parts to be included in the condensed conversation that I describe next.

Writing down stories transforms them, and breaking down stories is not in keeping with Indigenous worldviews (Iseke, 2013). While I had no intention to utilize a data analysis method that did this, I still needed to write down the co-creators' stories to be able to conduct an analysis which allowed me to make meaning and bring sense of the of the knowledge we co-created and provide a way of giving back the stories and my interpretations to the co-creators for validation. In keeping with IRM I wanted my data analysis method to privilege Indigenous ways of knowing and was decolonizing. This is why I chose Kovach's (2009) method in which a condensed story is formed by the researcher following the conversational knowledge sharing.

Using the transcribed data, I created a condensed conversation for each one-to-one conversation and one condensed conversation for the learning circle, using the women's own words as much as possible. I started with how the women introduced themselves and self-situated. I then captured what I felt to be the most significant part of their experience that they shared during the knowledge sharing session in terms of answering the research questions. For the researcher utilizing such a data analysis approach, the crucial part is to ensure true and appropriate voice and representation of the shared experiences, and then to give it back to the women in a purposeful and respectful way (Kovach, 2009; Wilson, 2008).

I mailed this condensed conversation document to the women and then called two weeks later to discuss the condensed conversation I had created and shared with them. At this phone call I corrected any errors the women identified, was able to validate my interpretation of their experience, and build a participatory element to the research process, as this step enabled the women to be co-constructors in the meaning making, which was important for ensuring the experience was given back to each in a purposeful and respectful way, as identified by the women themselves in our knowledge translation strategies.

Relational accountability was important as I wrote these condensed conversations, as my personal interpretation and meaningfulness of the analysis was dependent on the relationships I, as the researcher, had with the women. As I continued to strive to be a ‘co-resistor’, someone who supports the resistance of Indigenous Peoples to move from conventional approaches that do not serve this population well, I constantly questioned my motivations for choosing one part of the transcript over another, knowing that my beliefs and values would be impacting what stood out for me as being important to the story. This was a difficult process as it felt like placing more or less value on part of the story, I began to see how I was privileging knowledge systems and understanding over the other. I wanted to keep it all! The original condensed conversations were further built upon as meaning making continued and I started to notice common experiences. As I noticed these commonalities appear, I had lingering questions about their experiences. These key contextual realities were added to each women’s conversation and this updated document was mailed to the women prior to phase two of knowledge sharing.

Once the first version of the condensed conversation had been created and mailed to co-creators, I continued meaning making by developing detailed concept maps for each one-to-one meeting (see Appendix I). Braun and Clarke (2006) describe use of a thematic map to highlight the various themes and subthemes that are developed and a similar approach was taken here. I also created a concept map of my own personal learnings and to highlight the key learnings from listening to the stories of what it is like to live with HF. A final map was created following the circle (see Appendix J). Ultimately, I ended up with six concept maps from the individual women, my own concept map, and the map formed from the actions for change identified during the circle (see Appendix K). These detailed maps were used as the basis to develop the simpler maps which were shared with the women prior to the circle, as mentioned above. The condensed conversations and the concept maps, served to highlight three contextualizing realities from the women's experiences which will be presented in the subsequent chapter.

Based on these learnings I then created a document that enabled me to examine this information using a decolonizing lens and Greenwood's (2019) framework for cultural safety and health system change (see Appendix L). Doing so enriched meaning making, while also providing a mechanism for documenting change strategies and planning knowledge translation and mobilization activities. This step involved identifying structural, systemic, and service delivery components of the research questions. I broke this down into four areas: 1. How the women manage living with HF; 2. The determinants that impact their ability to live well; 3. Their experience with the health care system; and 4. Actional indicators for changing programs and services, and knowledge mobilization.

As a non-Indigenous researcher using IRM from a decolonizing standpoint, my reflexive journal was highly important to the methodology. I analyzed my journal, and created a concept map which highlighted the key concepts of my learnings from the women's experience and my personal and professional training. This process aided meaning making and also helped me frame what I had learnt about myself for sharing with the women during the circle. As such, the process of data analysis and meaning making began even at the proposal stage, with this inductive, iterative process being maintained throughout the knowledge sharing and making meaning process. I have shared some of the insights from my journal throughout this chapter but these learnings will be shared in greater detail in the following chapter as I present the findings from this work.

By journaling there was a constant movement back and forth from the text, to the experience, to the journaling, to help develop a deeper understanding of the women’s experience. Journaling helped me identify personal and professional feelings, where I felt I had made mistakes in protocol and was worried I had offended the women, or when I was feeling frustrated and ashamed of the health care interactions the women had experienced. It certainly highlighted the many times I felt vulnerable and doubting my worth in this work. Journaling also allowed me to document positive experiences and feedback I had from the women themselves, and from those supporting me, which helped with the self-doubt feelings and gave me the boost I needed to continue in this decolonizing approach, striving to become a settler accomplice that is acutely aware of the historical and traumatic relationship of Indigenous and non-Indigenous Peoples in Canada. My reflexive journal provided the means to document my role in the research, and my experience, as well as serving as a means of an audit trail. This is important to the decolonizing lens and to the methodology, as it upholds relational accountability and adds trustworthiness to the research, a concept I shall address shortly. Reflexivity is also important due to my role as researcher and in some cases as care provider to this group of women. Critical self-reflection enabled me to address the multiple social roles I occupied in this research, my privileged position, and potential power imbalances in my roles with the women participating in the research (Rix et al., 2014).

Concessions Due to COVID-19

Halfway into recruitment, the global COVID-19 pandemic began to impact the relational aspects of working with Indigenous populations. There were two main challenges here: One, the HFC was no longer seeing patients in person as the hospital shut down to essential services only. Potential recruits were no longer able to see the recruitment posters when they came to the clinic, which had served as a visual prompt for both patients and the nurses in the clinic to use the script. Appointments were being carried out by phone exclusively. Thankfully, the nursing team at RIH HFC were able to continue to recruit three more co-creators, but now the second challenge presented; due to physical distancing I would be unable to conduct knowledge sharing face-to-face. I wanted to continue the great momentum I had gained with the three women I had already recruited, but was concerned about respecting the methodology if I could not carry out face-to-face meetings. I decided I needed to venture forward as best I could and applied for an ethics amendment that would enable knowledge sharing by phone only, with a slight adjustment to the original consent form (see Appendix G).

Lupton (2020) served as a resource initially in the form of a crowdsourced document sharing experiences and literature regarding fieldwork in a pandemic. Moving face-to-face knowledge sharing to other technological venues and the strengths and challenges of this was being shared by many researchers, and served to echo the concerns I was having in terms of the impacts to building rapport, and the loss of non-verbal cues. Irvine (2011) had examined the difference in data collection in face-to-face- versus telephone interviews, finding no significant difference but acknowledging the lack of data examining this topic. The obvious challenges were highlighted; the reduced amount of small talk which impacts rapport but also means knowledge sharing starts sooner and sets a different pace for the time together; the concern for cutting participants off; and lack of non-verbal cues. However, Irvine (2011) and Lupton (2020) also served to highlight the benefits of telephone methods, with participants being home and willing to participate due to a reduced number of personal commitments that the restrictions had created for people. I decided the women themselves were the best to decide if knowledge sharing could continue this way, and if they consented to this means of knowledge sharing, then I was glad to continue. Paying attention to the relationships and checking with the women how to go forward given how pandemic distancing is foreign to Indigenous ways of knowing and being.

Three of the six one-to-one meetings occurred via the phone due to the pandemic. Knowledge sharing by phone did provide some challenges as I mentioned above. I found the removal of crucial non-verbal cues did sometimes make me cut people off too soon, or talk over them. I also felt it was harder to appear sincere in my empathy without these non-verbal cues. The first of these women whom I spoke with on the phone I also had never met in the clinic and I was concerned about the relational aspect of this, particularly due to wanting to respect IRM's relational processes as much as possible throughout this journey. However, given the need for several phone calls prior to the formal knowledge sharing, as had been the case with in person sessions too, these phone calls enabled us to start some relationship building prior to our formal recorded session. I had met the other two women personally in the clinic in prior years while I was still providing direct patient care in the clinic. Some of the audio recording was not as clear on the phone as it had been for meetings completed in person but this did not significantly impact meaning making.

Relationship building through telephone conversations during the knowledge sharing phase enabled the women to stay in the comfort of their own home, positively impacting the challenges with power dynamics between researcher and participant. Due to my work schedule, it provided greater flexibility in when knowledge sharing could occur. I also felt more comfortable having my notes in front of me in this format, felt freer to take notes about the experience, and protected me from revealing my vulnerabilities when facing women I did not know.

Just shortly after I had completed one-to-one knowledge sharing with the sixth co-creator, the province began lifting gathering restrictions and I was able to move ahead with planning the learning circle. Ethics amendments were made as the format of the learning circle had to be adjusted slightly, and a safety plan needed to be put in place. This safety plan included contacting the women the day prior to the circle to verify they were not experiencing any COVID-19 type symptoms. Finding a space that was taking room bookings, and that could accommodate a circle now with physical distancing requirements was easier that I thought and only took a few calls to arrange. The original plan of coming together and sharing lunch prior to the circle had to change to individually packaged food and beverages. This reduced the time planned for the circle and this may have been advantageous for some of the women that had travelled some distance to be with us. I was concerned that by not having this time prior to the circle, the women would not able to get to know each before the circle started. However, it did not take many minutes into our time together for the women and Colleen to realize that they had either met each other in some other circumstance or had family connections, so this lack of time together prior to formal knowledge sharing ended up not really impacting the circle at all, and reinforce the idea that everything is related and interconnected (Wagamese, 2013).

Trustworthiness

The concept of trustworthiness has been chosen to ensure the rigor of this research in keeping with the thoughts of Lincoln and Guba (1985) who discussed the irrelevancy of terms such as reliability and validity in qualitative research. In this sense, trustworthiness has four aspects: credibility, transferability, dependability, and confirmability. Each aspect has specific strategies that can document achievement of trustworthiness, and serve as “self-correcting” mechanisms if needed throughout each step of the research, rather than at the end when findings are reviewed and the opportunity to correct steps is lost (More et al., 2002). These self-correcting and trustworthiness building strategies include audit trails, confirming results with co-creators, and peer debriefing.

Audit Trail. Field notes and the reflexive journal I maintained served to document the research process as a means of audit trail, addressing transferability, while also providing an opportunity for self-awareness and consideration for my personal impact on the knowledge sharing and meaning making at each stage. I was able to review the transcripts, and the journal and identify any language that I had used that needed to be adjusted for following conversations.

Peer Debriefing. Parts of the journal, alongside the transcripts were shared with the thesis committee as a means of peer debriefing, as well as in person and video conference meetings for the same purpose. As well as debriefing, such meetings also provided an opportunity for my peers to review the data and challenge my thoughts about meaning making, considering different perspectives and worldviews, and how my worldviews had led to the conclusions I had drawn. The committee ensured I was examining my understanding, pushing me to think deeply as I began to unpack my interpretations, always striving to explore the intersections of what it means to maintain trustworthiness and a decolonizing lens in relation to power. Knowledge Holders Gwen and Colleen also provided peer support and debriefing, advising on culturally relevant protocols, helping challenge the influence of my worldviews on meaning making, and ensured I was working towards being a settler accomplice and co-resistor by shifting power to the women, and learning from and centering the knowledge shared by the women themselves.

Confirming Results with Co-creators. The women were all given a copy of their condensed conversation and concept map, where I had identified what I perceived to be the key learnings and this provided a means of member checking and for confirmation of intended meaning with the women themselves. Descriptions and quotes in this written report where I share my findings, and any subsequent writing about this experience and our findings provides insight into how I came to my analysis and interpretation of the data, which addresses transferability and trustworthiness in general (Polit & Beck, 2017).

In addition to the steps above, trustworthiness in IRM is upheld by addressing relational accountability and the principles of respect, relevancy, reciprocity, and responsibility: the four Rs (Bourque bearskin, 2016; Kirkness & Barnhardt, 1991; Kovach, 2009; Kurtz, 2013; Rix et al., 2014; Wilson, 2008). The principle of respect was met by including Indigenous worldviews, beliefs, traditions, by the sharing of knowledge in a culturally appropriate way, and by building relationships in doing so. I upheld this principle by using a decolonizing lens and Indigenous methodology as the foundation for this work. In keeping with the first R, the learning circle protocol followed local protocol as directed by Colleen leading the circle. As well as ensuring respectful practice, such protocol further helped address power imbalances, as everyone is perceived to have an equal say in the circle.

The principle of reciprocity was addressed as I considered the power dynamic between myself as a non-Indigenous settler nurse researcher advocating for the creation of services and programs that meet the needs of Indigenous women, based on what they identify to be their needs, thus contributing to self-determination, and giving back to the community. The principle of responsibility was met as I enacted my accountability to both the individual women and to my fellow health care professionals impacted by this research.

Finally, the principle of relevance was addressed, with the literature review supporting the relevancy of this research, demonstrating a need for research that gives Indigenous women with HF a voice so to develop relevant programs and services that meet the needs of Indigenous women with HF as identified by themselves (Howell et al., 2016; Snow et al., 2016). The relevance that I felt existed from what I witness in practice, and was further supported in the literature review, certainly was reflected in the conversations I had with the women. The more conversations I had with the women, with Gwen, and the thesis committee, the clearer it became that this relevancy was also shared by those involved in this local context, as many of the contextualizing realities that were emerging in meaning making were confirmed in my literature review.

Alongside adherence to the four Rs, and trustworthiness with IRM, I was confident that the use of reflexivity throughout the research process would help me to articulate ethical issues and tensions I experience working within diverse populations. (Lavallee, 2009; Rix et al., 2004; Tuhiwai Smith, 2012; Wright et al., 2016). My reflexive journal provides a documented account of how I examined my own assumptions and beliefs, and considered factors such as my social location, position and intentions of my multiple roles, and power dynamics throughout the study, alongside my thoughts, feelings, and observations during each one-to-one session, the learning circle and the research process, and I shall continue to weave these reflexive thoughts and experiences throughout the subsequent chapters. Reflexivity became my decolonizing lens where I intended to alter the power relationship to focus on partnerships between myself as the researcher and the women co-creators, by constantly critically examining my role and influence.

As documented above, co-creators were given a copy of their individual condensed conversation and the concept maps I had developed. Those who attended the circle were given a copy of the condensed conversation of our knowledge sharing and the recommendations suggested by the group identifying what Indigenous women need to live well with HF. Giving back the data in this way enabled co-creators to confirm the intended meanings of what they shared, and examine my interpretations of what was shared, to clarify and verify meaning and recommendations. Giving back the data in this way provided a strategy for ensuring trustworthiness as documented above, while also addressing relational accountability, addressing the four Rs, and providing an opportunity for the women to co-construct data analysis and knowledge translation (Jacklin et al., 2016). I considered that the literacy levels of co-creators may not be the same as myself, of university education, and thus wrote my analysis in plain language, avoiding medical jargon.

Ethical Considerations

Ethics approval was obtained from TRU and RIH research ethics board, through the harmonized ethics program with TRU as the primary site for ethics approval, certificate number H19-03728. An operational impact assessment was completed at RIH with subsequent operational approval. In keeping with IRM attention was given to local and cultural protocol as well as ethical protocol (Kovach, 2009). My primary responsibility was to do the right thing and avoid harm to the women who agreed to participate and share their experience. The Tri-Council policy statement (TCPS) for ethics when working with Indigenous Peoples require adherence to the four Rs (Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC) , 2018).

This research does not involve a specific Nation as the HFC serves multiple Indigenous communities and Nations within the IHA region as documented in Chapter One. The community in this case includes Indigenous women with a common experience of living in the Interior region of BC, living with a HF diagnosis, and who access the HFC at RIH. These women are therefore considered a community-of-interest, whose ethical obligations are supported as above with the guidance of Knowledge Holders and the thesis committee (Kovach, 2009; Tuhiwai Smith, 2012). The women who expressed interest in participating after the initial recruitment phone call were mailed the written consent form to review prior to making any arrangements for knowledge sharing. This consent form was reviewed at a subsequent phone call where verbal consent was obtained alongside making arrangements for where and when knowledge sharing would occur. Prior to the commencement of individual conversation sessions, the written consent form was again reviewed and signed by the women. When completed on the phone verbal consent was documented on the consent form as being received by the researcher, and on the transcription of the audio recording. Ongoing consent was verified verbally prior to the commencement of the learning circle. At each contact it was made clear than non-participation would carry no negative consequences or benefits to care for these women within the HFC. This was important given the role of the researcher as a former nurse clinician within the clinic. Dual roles can create power imbalances and I took steps to prevent jeopardizing my role as researcher and participant with patients that I may have provided nursing care to (Rix et al., 2014). As previously mentioned, the steps I am taking to decolonize myself and the reflexive journal were key to mitigating any power imbalances.

The physical location of both the individual conversation and the learning circle is important to address the power dynamic, and is the primary reason a non-medical location was used. The safety of the researcher was considered for knowledge sharing that may involve travel to remote and rural communities or which may occur in private homes. This only happened for one woman, and a risk assessment was performed and the procedure for phone check in that had been established during the proposal stage was followed (see Appendix H).

At the time of phone screening for inclusion prior to obtaining verbal consent from the women, I identified myself as both the researcher and a former nurse providing care to patients in the HFC, giving the women an opportunity to decline participation if they felt uncomfortable with this. As it was expected that third-party recruitment would likely provide the largest number of potential co-creators, and may occur as other nurses and health care professional working within the clinic are asked questions by those who see the recruitment poster, a script was provided to ensure any potential third-party recruitment did not unduly influence participation.

Data security was an important consideration. All transcribed data from individual sessions and the learning circle, as well as any data analysis documents were stored on a secure password protected computer accessible to the researcher only, to protect the women's confidentiality. To further protect confidentiality, co-creators were given the option to use a pseudonym in any written documents produced. Written consent forms were secured in a locked cabinet, in a separate place from the data collected. Consent forms will be kept for five years and then shredded for safe destruction. Confidentiality and respect for other individuals was also protected by following the protocol of the learning circle as identified by Colleen.

The First Nations Information Governance Committee (National Aboriginal Health Organization, 2007) developed and trademarked the OCAP™ principles concerning the creation and management of information in Indigenous research. These principles of ownership, control, access, and possession, incorporate the belief that knowledge and data derived from Indigenous research is collectively owned, Indigenously controlled, and with Indigenous Peoples having the right to make decisions about what to do with this information (Morton Ninomiya et al., 2017; Schnarch, 2004). The Indigenous women involved in this study were involved in how the information was created, how it will be shared, and on what terms.

Potential harms that were identified prior to knowledge sharing, included the emotional consequences of sharing a lived experience and the potential of co-creators to arrive to the session acutely physically unwell. Although it was the hope that the learning circle environment was more conducive to sharing of their lived experience and that co-creators would gain emotional support from sharing their stories with each other, there were plans put into place should negative outcomes occur. If co-creators experienced emotional distress as part of the research, or came to the circle in emotional distress this was to be dealt with by Colleen and by the researcher supporting co-creators in accessing counsellors or other services as deemed appropriate by the participant and Colleen. The researcher had a list of counselling services the women could access if needed. Should a participant have arrived acutely unwell or become unwell during the learning circle I would have supported them in accessing medical care, either emergent and urgently, or supporting connections with primary care providers.

Knowledge Translation

Western notions of knowledge translation (KT) do not fit with Indigenous ways of knowing (Morton Ninomiya et al., 2017). For Indigenous Peoples, KT is very much part of the tradition of passing on knowledge and is not a new concept to their worldview. Indigenous KT involves “sharing what we know about living a good life” (Smylie et al., 2014, p17). The CIHR (2009) acknowledge this difference in notions of KT and describe Indigenous KT in terms of the K representing the recognition and understanding of Indigenous knowledge systems, and the T representing putting the K into action by engaging communities, increasing community capacity, and local relevancy. When joined together, Indigenous KT links to addressing the underlying determinants of health and incorporates knowledge into existing or new programs and services.

The women of this study are co-constructors of the knowledge we shared and the meaning we made from it. As such, they were influential in suggesting appropriate ways to share the findings with the Indigenous community, health care professionals, and health authority leaders. The women were invited to be involved in KT to aid with participatory approaches that are both decolonizing and imperative to Indigenous knowledge creation. KT strategies, understood as knowledge translation and mobilization approaches by the women themselves, will be discussed in Chapter Six.

Chapter Summary

In summary, throughout this chapter I document the theoretical underpinnings, methodological details, and sequence of events for how knowledge sharing and meaning making occurred during this research inquiry. I addressed the ethical considerations and the concessions that were made due to knowledge sharing occurring amidst a global pandemic. Now let us turn to the findings from the women themselves.

Chapter Four

Findings

In sharing conversations and making meaning, I witnessed the historical and ongoing impact of colonization on the lives and wellbeing of the Indigenous women involved in this research. I further gained a deeper understanding of cultural safety and humility through understanding the women's experience of living with HF and accessing health care services. Many common elements were seen throughout the women's experiences and stories, despite their diversity in background and geographical location. The women's conversations and experiences in their own words are the most significant learnings for this research (see Appendix I). As I write about the knowledge the women and I co-created, my personal reflections from my reflexive journal are threaded throughout to demonstrate how using a decolonizing lens has supported my ability to make meaning from the women's experiences and gain a deeper understanding of allyship and cultural safety. Throughout this chapter, the words of the women as co-creators appear non-italicized, while my personal reflections are italicized to help distinguish the two. The women were given the choice as to how they would be identified in written reports. The names used here are a reflection of that decision by each woman.

The experience of being an Indigenous woman with HF is complex, rooted in trauma and the key context of the women's stories identified during our conversations all intersect with each other. While trying to reflect the women's voices and provide a logical presentation of the findings, I discuss what I gleaned as three contextual realities: **1. The experience of living with HF**; **2. The influence of the health care system**; and **3. Moving forward in a good way**. I begin with the context of focusing on the experience of living with HF, which includes consideration of what is needed to live well with HF, detriments to wellness, and the day-to-day influencers of health and wellness. Next, I present my understanding of the contextual realities these women face and the influence of the health care system specifically. I conclude the chapter with the context of considering moving forward in a good way, and what the women themselves identify as needed to meet the needs of Indigenous women living with HF. Moving forward in a good way is a common aspiration that Indigenous Peoples have been calling for since the dominionization of Canada (Restoule & Chaw-win-is, 2017; Vaandering, 2015).

Contextualizing Realities: Living with Heart Failure

Living with HF involves an underlying holistic approach to health and wellness, which was strongly evident as the women shared examples of meeting physical, emotional, mental, and spiritual needs, as well as barriers to meeting these needs. The interconnectedness of the dimensions of health and wellness from an Indigenous perspective is shared by Dell when she said "you have to have clarity…. we need our walks, our food, our spiritually, mentally, physically we have to get all that for it may help your heart". All women spoke of the benefits of walking, and other physical activities such as yoga or Tai chi for wellness. The importance and benefits of activity was beautifully spoken by Dell when she stated:

> Other healing, well you've got to be active, get off your butt and do something outside. Walk, walk, walk, that's the secret of life. You got to be active. You got to keep your heart pumping. To get all that beautiful blood over your body.

Alongside activity, food was a common consideration when living with HF, in terms of accessing healthy foods, and traditions centered around food. Margaret and Dell shared memories from their childhood of large gardens, of hunting and fishing, and canning and smoking of food as a family and community activity. Dell said "we didn't go to all these big stores; we ate what we grew". Connecting this physical need for food with meeting other needs through being with the community and traditional practices centered around food is demonstrated by Dell as she went on to say "in the community garden, we connect and we do like a big dinner or like get together or pot luck, then we get veggies from the garden and the men go out hunting". The impact of colonization on such traditional practices is seen when Dell shared the challenges of engaging the community to come out and take part when she said "It's different this day in age because it's so easy to go to the store and buy it, people would rather have things easy".

Talking with Marilyn about food she stated "I notice my health is a lot better since I cut down on the sodium, fatty foods, and stuff", suggesting food was important for meeting her health and wellness needs. Marilyn further went on to say "it's hard to eat healthy, my kids eat a lot of stuff in front of me. It's tempting. I did fall off a few times". Marilyn's experience shows the relationship between the emotional and mental impact food can have. Marilyn then added "It's expensive for me, because I buy a lot of veggies", which highlighted the issue of food insecurity.

These conversations about traditional food practices and holistic approaches to wellness led to contemplating my experience of learning on the land during one of my graduate classes. *Learning on the land was an opportunity to feel the connection to the land in a way I have never done before. I have taken the land for granted with little consideration for its impact on health and wellness* (Journal entry July 12, 2019). As I further reflected on this entry later into making meaning:

> *I realize these reflections of acknowledging how much I take for granted, how my thoughts are influenced by always having access to the resources I need, just how easy it is to go to the store, while well intended when I wrote them do nothing to help with*

> *decolonizing and allyship. Because what the women's stories really represent here are the impacts of colonization and the unjust distribution of the determinants of health. So rather than acknowledging what I have, and how privileged I am to have it, I'm moving towards anger that so many people in society do not have access to basic determinants such as food, and shelter. This change in my thought process is pivotal for my personal growth towards decolonizing.* (Journal entry December 5, 2020)

The idea that the land could be a determinant of health (Lines et al., 2019) reinforced my ideas on the role of traditional healing practices and ceremony as an important part of holistic approaches to wellness and living with HF which was shared by some of the women. Some shared the traditional medicines they use in their daily lives while Margaret spoke of how she has not been able to attend traditional ceremonies as she had in the past due to her symptoms, and the accommodations she has made to still be able to meet her emotional and spiritual needs, when she said:

> I can't breathe with the smoke from the fire. And they ask me to come to the sweat, but I can't breathe because of the heat. So, I just have my prayers, my congregation, my meditation, my eagle feather, my rocks, and I go to the river if I can.

Emotional and mental health needs were expressed as the women shared the importance of keeping a positive attitude despite the challenges they faced. As Margaret said "negative thinking keeps you sick.". Della spoke of trying to "be the best you can be and make the most of it". Emotional and mental health concerns were expressed as the women spoke of feeling overwhelmed, scared, and worried about their health and wellness, and the future. For example, Marilyn said "having all these appointments lately, I'm kind of overwhelmed". While SLC shared she worries that she "might not be around next year".

Many women spoke of living with significant grief, and stress throughout their lives. All reported significant loss of family members, some including their own children, and often these losses were due to violence, while some spoke of the impact of residential schools. Marilyn shared the impact of stress when she said:

> I've been stressing out about stuff, with my heart problem, and stuff, I'm dealing with having to take all these pills every day, dealing with parenthood and grandparenthood, and stuff. Believe me I know what stress does to you.

Delwiese raised the impact of stress when she said "I thought I was having a heart attack; it may have just been stress". Margaret also stated "I have a lot of stress. I always said I wasn't stressed out, but I guess I was deep down".

Considering grief, stress, and trauma links to the experiences shared by two women which impacted belonging and subsequently identity. The impact of being raised away from home Nations was most profound when listening to Marilyn as she shared:

> My mom didn't really raise me; I was in a ministry home since I was born. I've noticed it distanced me and my mom, she doesn't look at me like her child anymore, so its kind a put a gap there being raised differently.

Della shared about being removed from her mother at birth and raised with a white foster family. Della firstly shared why she was fostered rather than adopted when she said "take her as a foster child they give you 150 for me every month to help support me". Della had siblings who were raised with her grandparents but shared "They couldn't afford to take me". Della then went on to share:

> When I was growing up, I always felt that I had, would have liked to had the chance and know what it was like to live with the native people, to my knowledge I feel that native

> people live a bit of a different lifestyle than the white people. When they go to school, they're talking a bit different than their other cultures, than what I learnt in going to regular school. Since I didn't grow up with the native people and I grew up with a white family and I went to school with regular kids, I wanted to keep my distance because I didn't want to get the two mixed up.

Margaret and Della's experience enabled me to see first-hand the effects of colonization on belonging and identity. Even though Indigenous Peoples have been speaking their truths since the release of the TRC, (TRC, 2015) I wonder how could I have missed this reality. Hearing these stories was emotional and made me think about my connections and belonging:

> *I am an immigrant. I have experienced leaving my home land and those that support me. However, this was my choice, and I maintained my privileged position in doing so. Moving for me did not cause the same detrimental impact to my belonging as it has for so many Indigenous Peoples who have had to move, or were removed from their land and Nations.* (Journal entry September 5, 2020)

As I later reflected on the above entry I noted:

> *…my experience of being an immigrant really demonstrates white privilege in full effect. This makes me think back to early journal entries about how I learnt about Indigenous Peoples when I first became a landed immigrant, and particularly the concept of the benevolent peacemaker myth. Since I started this journey, I have attempted to share my knowledge with those who don't know. I recall a conversation with my parents, who also became landed immigrants a few years ago, and they had no idea about the treatment Indigenous Peoples had faced at the hands of European settlers. In sharing with them I was able to use my white privilege for social justice in a small way. If we all learn and*

> *share, each of these small steps would be a big leap in reconciliation.* (Journal entry December 5, 2020)

The impact of living with the symptoms of HF was poignantly shared by Margaret when she shared how “the heat bothers my breathing, and when it’s too cold it bothers my breathing, so in the house is the best temperature. It’s not a very good way to live”. The impact of symptoms on daily life was even more evident for those living with multiple health challenges. SLC shared her difficulties when she said:

> I don’t check every morning either [referring to her blood sugar]. on that, because I have a heck of a time trying to press that. And that’s another thing too. Those support socks I got [referring to her compressions stocking to help with her swollen ankles], there’s no way I can put those on. Like even my orthotics, if your arthritis is so bad how are you supposed to take them out every morning and push them into a new shoe?

The challenges of living with a chronic condition and managing symptoms while occupying multiple social roles such as wife, parent, grandparent, while working, or maintaining domestic roles was expressed by some. Several of the women were raising their grandchildren. Some women shared the health concerns of other family members and the impact of this on them. Margaret shared her husband’s health concerns and how this impacts them when she said:

> My husband is dying also, he’s got cancer. We’re not dwelling on it. Like some people dread the thought they’re going to die, and get really worked up about it, and sad about it, but I’ve been sick for so long, that its life happening, if you can’t get fixed, you can’t.

Delwiese spoke of her husband’s feelings about her health challenges when she said “it bothers him”.

Many women proudly spoke of working from a young age and the loss of the ability to do paid work or fully participate in domestic responsibilities. Sharing the loss of independence with these responsibilities highlighted the lack of supports to help with these responsibilities when individuals are no longer able. Delwiese shared, “I’ve been busy my whole life, my house was always spotless, but now I can’t”. Margaret shared a similar experience, talking about cleaning her home she said “I can’t breathe good enough to do it. I can’t do what I want to do”. SLC shared “I wanted to do some laundry and I couldn’t, even one of those shopping bags was too heavy for me. It’s even harder to get somebody to come cut your grass”.

Summarizing the learnings related to the context of living with HF, the women’s conversations highlighted; the importance of holistic approaches to wellness, of an Indigenous perspective, and traditional beliefs and practices; the impact of grief, stress and trauma; situations that negatively impacted belonging and the consequences of this; the day to day challenges of living with the symptoms of HF and other chronic conditions, and the struggles to maintain social roles and responsibilities and the lack of support in doing so, and the challenges with carrying out the monitoring that health care professionals ask. For the Indigenous women in the study, these daily challenges are in addition to living with the effects of colonization, racism, and inequitable access to determinants of health. What is most alarming is that there is more than enough evidence to show the impact of a lack of access to health services and that change is greatly needed (NCCIH, 2019).

Contextualizing Realities: Health Care System Influence

The women shared positive experiences when receiving health care, which occurred in situations where they felt listened too, supported, and understood what was happening. For instance, Marilyn said “when I got my surgery in Vancouver, Dr xx and his assistant, his assistant was really nice and he explained to me properly why I had to take the pills and stuff". Delwiese said "the heart doctors that I was seeing in the hospital were letting me know what was really happening". Dell talked of her experience in the USA when she had her first heart attack saying "they were really nice in San Diego, the doctors, they explain everything, what they're going to do to you, what's going on". Margaret, referring to her encounters at the HFC said "I liked the lady doctor, the lady doctor seemed to explain more to me".

Despite these noted positive experiences, a more commonplace were experiences of not feeling listened too, of being rushed and not having control over what was happening in the health care environment. How an interaction was perceived was primarily dependent on the individual health care professional like SLC said "some people are really good and some people won't do anything for you", and Margaret stated "I guess it really depends on who the nurse is". Marilyn shared her feelings of a conversation with clinical staff about titrating her HF therapies when she said "I had to higher my heart pills and she explained to me but she was going through it so fast, I was just like, holy that was weird". Delwiese shared a similar experience when she said "he just didn't have no ears, didn't see my view… he didn't have enough time". Dell similarly stated "so much difference when people don't listen, don't care".

Dell shared her thoughts about the power health care professional hold and not being listened too when she said:

> Doctors, they figure they're right all the time, and if little me say oh I know what's wrong with me they say I have no right to talk and tell them what I think, you can't diagnose what you are. I tell you this is what's wrong with you.

SLC shared her thoughts about an interaction with a physician that demonstrated how health care professionals hold power and make judgments about people when she said "next thing that comes out of his mouth, oh you're a little heavy. I say to myself, this doctor I'm not getting anything out of him".

Several women spoke of conversations where the language used by health care providers negatively influenced their care, and demonstrated how the language used in healthcare privileges biomedicine. Dell said "I hate to call it heart failure. Heart failure is a death sentence. Call it a challenge. Words can mean so much". Delwiese shared a similar belief when she said "I didn't like that term (failure), it sounds pretty fail to me". Delwiese suggested instead "put it in softer terms but tell them it's serious and explain, be up front about everything". The influence of language was also seen when Della said she was asked "are you eating okay and drinking okay?". I considered this in my journal when I reflected *what is okay? Nurses need to consider how they ask questions and the kind of information they are trying to elicit and the relevancy of the questions* (Journal entry April 6, 2020). The dominance of imposing biomedical language in health care interactions and how words are interpreted is reflected in Della's conversation "these few things I can't have [referring to food], can I have them once in a while? They told me I couldn't have them at all". This dominance of knowledge systems is explained by Kennedy et al, (2020) as an approach that supports the maintenance of oppression and silences Indigenous views.

The women shared many examples of not understanding what was happening in health care interactions. Margaret said "the doctor really didn't say much to me, they think I can't handle it". Della shared her feelings during an admission to hospital with HF when she recalled, "I really don't know what this is all about. I couldn't figure out…they didn't explain…. nobody told me anything. I was scared stiff cause I didn't know what was going on". Margaret shared her thoughts around this, saying "native people have the knack of not asking too many questions because we've been told to be quiet so much. So, we don't ask, we don't say, and we don't understand". Della repeatedly in her conversation states she did not understand what she was being told. As Della shares her experience of requiring an implanted cardiac device she states "they didn't explain where the pacemaker is, I had no idea what I was in for". Della further adds "I couldn't think of the questions to ask and that cause I was kind of dazed cause it happened so quick" and "nobody told me anything, I was scared stiff cause I didn't know what was all going on".

In addition to poor communication and misunderstanding, there were experiences where the consent obtained was questionable. Dell shared of an experience when she had Quincey and her tonsils were removed without consent:

> They opened my mouth, I could barely open my mouth, he stuck the scissors in my throat and he cut something. I was crying because it hurt so bad. When that doctor came, he just looked at me and he didn't say oh I'm going to lance it or try to lance it or something. I would have said no. Finally, I put my hands up and shook my head no, I wrote on a note put me under and so they did. I woke up the next day, opened my eyes, he left, he took off, he didn't come see me. He sent these three doctors and they said oh by the way we took out your tonsils, I go like what! My God. He took my tonsils out? What! Who does that when you're under? Without permission or nothing.

The women provided examples of the health care system agenda being placed ahead of their individual needs. Often the women were not given an opportunity to choose what was discussed at health care interactions, or address the factors that were impacting their health and wellness. This was prevalent when conversing about care received in the clinic, which focused on medications and the self-management education. Biomedical treatments and interventions, including prescription medications are a central intervention to HF management, and concerns around medication use was raised by all the women. Delwiese said “I’m pleading to get off medication. I don’t really like taking medication if it’s not needed”. Marilyn stated “I’m not 100% on board with taking pills”. Dell stated “this is my body, don’t put things in there because I don’t”. Concerns with medication use were multifaceted, with some not understandings what the medications was for, for some the side effects from the medication were worse than the underlying condition, and for some medication conversations made them feeling experimented on. Dell shared “when they put me on this last one here that made me so sick and nearly die. They don’t tell me the side effects or explain to me this is going to happen, or why ‘I’m on it”.

In addition to prescription medications, central to supporting those living with HF from the treatment perspective involves the self-management philosophy and patient education which is achieved with the support of the “Living with Heart Failure” binder. When asked about the binder Dell said “it was very helpful honestly, I did learn a lot” and Margaret shared “I like that book. It was very good information. It talked about the medication, the ups and downs if you drink too much water, and what to do if you’re bloated and have swollen feet and that”. Yet, several reported the binder was given to them with no context to its purpose or not reviewed by the healthcare provider who had given it to them. For example, SLC stated “she gave me this book and said bring it every time I come in. And then we didn’t even look at the book when I brought it in the second time”.

The dominance of the self-management philosophy was evident in my conversations with the women as many examples of how the women were “complying” with the teaching even if the teaching was not relevant to them. Marilyn stated:

> I'm sticking to the diet they have at the clinic where you have to read your food label and don't have food from the box and don't eat food from the can. I will take care of myself: I will do what it says in the binder.

Delwiese shared a similar thought about doing what the binder said when she said "I eat pretty well; I don't over indulge". These comments from my first two co-creators were concerning to me:

> *I don't want the women to feel my conversations are about their compliance to lifestyle coaching and behavior change, but when I ask about the content of the binder and its relevancy this seems to be the outcome. Is this because the women expect me to privilege the Western ways, to not want to hear if this was not relevant to them, that they need something else?* (Journal entry February 11, 2020)

Reflecting on my February 2020 entry I realize now:

> *Considering how self-management education was interpreted as not being a choice links to determinants of health and patients being labeled as non-compliant with self-management even if the reason for this perceived non-compliance is due to socio-demographic factors that the health care professionals have not addressed, or that the teaching is not culturally relevant. This is due to white privilege, and the dominant view of Western biomedicine being implemented daily with no consideration for other worldviews or determinants of health which impact Indigenous Peoples.* (Journal entry December 5, 2020)

Della's conversation demonstrates how health care professional's communication impacts the relevancy and meaningfulness of educational material when she said:

> [T]hey gave me that binder, and she explained a little bit about that binder but I still didn't understand why I needed the binder. She did say something about I have to cut back on this and this. I'm thinking what? Why I have to cut back on certain foods? I went home thinking nothing of that, and I just went and ate whatever I felt like eating.

Della further stated "I don't really see the point why I can't have this stuff, because it didn't bother me when I had the hamburger or whatever. If they did explain it to me, I didn't see it".

HF self-management teaching prioritizes daily weighing for managing fluid status and weighing was an area of misunderstanding and miscommunication for many. Marilyn's response to being asked to weigh daily demonstrated not understanding why this may be relevant for her, and her concerns about body imagine in doing so were not addressed by clinic staff as can be seen when she says "it would make me feel self-conscious, like I would turn into a bulimic person. I wouldn't eat. I would just, it just kind a threw me off, they were pushing that on me". Some of the women shared the mixed messages given by health care staff regarding weighing daily and the purpose of this, with two of the women being advised by dieticians not to weigh daily because their weight was not a health concern. Della said:

> I didn't realize why I needed to weigh myself. For the last three and half, four weeks I've been weighing 112. I wonder, well, will I always weight this amount? Will I be able to gain some more weight?

Dell shared "I was told by the nutritionist not to be weighing all the time, and so I backed off, I'm not really worried about my weight."

Feeling rushed, not listened too or their input for the agenda not sought or valued, and subsequently not understanding what is occurring, leads to patients feeling disengaged in health care interactions and this is exactly what Marilyn felt when she shared that she "didn't pay attention". Della reported a similar feeling of disengagement when she said "I really didn't pay that close of attention, so I didn't know". Contemplating this after talking with Marilyn I wrote:

> *Patients mentally check out and health care providers just continue with their agenda. I have likely done his many times with no consideration for the needs of the patient in front of me, or how this interaction will influence future interactions and accessing care. This shows how strong the professional socialization of nursing is.* (Journal entry March 2, 2020)

As I later reflected further about the professional socialization of nursing I wrote "*One of my greatest learnings from this journey has been questioning professional socialization, reminding myself of the way whiteness influences my way of being when I interact with non-white patients, and making a significant effort to be anti-oppressive and anti-racist in all my encounters* (Journal entry December 5, 2020).

As a health care professional, and in my role of coordinator for our clinic *I am dissatisfied and embarrassed with the services we are providing when I hear this lack of explanations for treatments, and patients feeling rushed* (Journal entry March 16, 2020*)*. I went on to note:

> *I'm noticing how hard it is to turn off my Western bias towards the importance of self-management teaching as I get so frustrated hearing stories of poorly explained teaching, but then I remind myself these concepts may not even be relevant. So rather than focusing on being mad at the nurses for being ineffective with their teaching of what they feel to be important, I need to focus on creating health care interactions which support addressing the needs of patients as identified by themselves.* (Journal entry June 11, 2020) *With*

> *further learnings this would involve providing health care interactions which are anti-racist, anti-oppressive and culturally safe.* (Journal entry December 5, 2020)

Several conversations demonstrated the challenges for Indigenous women to manage their health and wellness between both Indigenous and Western worldviews. When conversing with Margaret a concern of mixing Western and traditional medicine became evident as she said:

> When I was in the hospital with my lung condition in ICU hooked up to all these machines, I was really sick. My oldest son came in there. He brought his medicine in and I didn't like that. He brought me some soup that I didn't drink because I didn't know if there was anything in it.

Della shared a similar experience when she spoke of her brother bringing her a cough medicine he had made and her wanting to take Western medicine instead. Della said "I'll take a cough syrup from my own doctor here in town but to actually take medicine from my brother and his native ways I just didn't feel right about that cause I don't know their system".

The women shared mixed reactions regarding thoughts about seeing Indigenous culture reflected in the clinic environment and teaching material. For Delwiese, "the generic stuff was okay", stating the relationships with the health care professionals and the interaction was more important than seeing Indigenous people reflected in the teaching material. By contrast, Dell said "the culture should be reflected in there, traditional foods, and like um, maybe recipes". Margaret also suggested traditional foods and recipes that are simple for people as being a beneficial addition to the educational material. Margaret and SLC both mentioned seeing their culture reflected in the physical space, as a welcome addition that may build cultural safety. SLC said "when you go into the waiting room for x-ray, they usually have some native art in there and I enjoy seeing some of that." Margaret similarly stated that it "would be nice, to see some on the walls, like the art in different areas".

As I contemplated the women's thoughts about seeing Indigenous culture within the health care setting, I noted:

> *I assumed all Indigenous people would feel more culturally safe if their culture was reflected, and was surprised when they said they didn't need to see it. Given the genocide of traditional knowledge and the ongoing effects of colonization I shouldn't be surprised. I should also not have assumption.* (Journal entry February 11, 2020)

I further wrote:

> *The women do not expect to see their culture reflected in health care because it's never been there and in assuming the women wanted to see their culture reflected, I was essentializing culture and ethnicity which is not what cultural safety is about.* (Journal entry April 4, 2020)

Such an essentialization of culture became prevalent when I considered my behavior in this research in the way I was gifting tobacco at the start of the conversations. It was not until after the first few conversations when I reviewed the transcripts with my supervisors that I realized I was not giving the women an opportunity to not take the tobacco, that it may not be culturally relevant for them. I wrote:

> *This [referring to my research journey] has been the best means of cultural safety training. For the first time in my professional life, I have contemplated my world views, the impact of whiteness, my privileged position, and power dynamics in interactions with patients.* (Journal entry September 5, 2020)

As I was making meaning about the tension of living as an Indigenous woman, I found I was struggling with my own tensions of this also. On July 30, 2020 I wrote:

> *I'm torn about two-eyed seeing. I see the benefits of the notion of using the best of both worlds, however, why is IRM in itself not enough? Both in research and my earlier thoughts that traditional healing being incorporated into Western health care would be beneficial for cultural safety and addressing health inequities. To be truly decolonizing shouldn't Indigenous ways alone be enough? Is two-eyed seeing a compromise? But a step in the right direction?*

Stigma, racism, and discrimination are known to negatively impact access to health care for Indigenous Peoples (Phillips-Beck et al., 2020) and this is reflected in Marilyn's conversation, "one time I was disrespected when I collapsed and the doctor made it sound like I was a really bad alcoholic, like maybe I wouldn't have as much surgeries and stuff". Delwiese shared her experience of a hospitalization when she said "I was being harassed… they kept on harassing me, putting me in isolation all the time, and so they had to gown up and that's when they didn't want to help you in anyway, it's a bother to them".

Lack of access to services due to distance, time, and cost was raised as a concern for some of the women. Some had no primary care provider, while Delwiese and Margaret travel forty-five minutes to see their GP, and SLC travels over two hours. Marilyn shared leaving her home Nation due to needing "to be closer to the hospital", and other women shared they had moved due to their health also. Delwiese spoke of the possible delay in diagnosis when living in Northern BC, "at the time they didn't find out that I had a hole in my heart there because they didn't investigate in depth like they do here in". Suggesting some of the diagnostic services that are available in tertiary hospitals are not available in Northern parts of the province.

For those living with multiple conditions, the lack of access to services was even more evident. SLC shared her experience of accessing services, stating she will line up two or three medical appointments for the same day because:

> I get a ride from tribal; they take patients out. And so, they kind of like it when I can get everything done in the same day. Cause I figure well it takes us two hours to get up there to go into an appointment for fifteen minutes and come straight home, like, what the heck, you know?

A further challenge with appointments was raised when SLC said “one other thing too, like um, why give us patients that have to drive into Kamloops, like you know maybe two hours, why give us like a 9-o clock appointment in the morning?” This comment highlights the health care system prioritizing its own needs and structure, and not that of those accessing services.

Jurisdictional challenges in accessing health care were raised by some as Dell astutely stated “people off reserve are ‘SOL’”. SLC said “Cause I’m from Boston Bar band and not Lytton band they don’t you know, like Tribal, they’re the ones that offer people rides to the hospital but the Lytton Band themselves they won’t even go through Tribal”. Dell acknowledged the challenges of accessing health care in her home Nation but further added “it’s hard accessing care anywhere”. Margaret shared her experience of accessing services in her home Nation when she said:

> They come in for 1 hour a week which I thought was too short and too little of a time, they should be doing more because they get all this money from the government and I don’t know what they use it for. They have a nurse that is in her office, they have bathing if you want to go there. They do shopping, but it’s when they want too, are able to do it.

> They pick up medication but it's always at the wrong time. There are things they could be doing better. I think they could care more.

I contemplated the challenges of accessing services within communities and Nations after several conversations. The extent to which white privilege and colonialism are embedded in the language of science, medicine, nursing and health contributed to the subtle and insidious forms of racism in the nursing profession (Smith, 2019). I was shocked to hear the women speak negatively about services in their home communities and initially worried about how I as a white person share that. In an earlier journal entry, I acknowledged, *it seems just as hard to navigate services within home Nations as it is in Western services, another double disadvantage for Indigenous people* (Journal entry May 28, 2020). As making meaning progressed it became clearer to me that:

> *…jurisdictional funding and the impact of this on the services available to Indigenous people living in urban areas and within Nations is one of the root causes of disparities for Indigenous Peoples, an area where meaningful change at the structural level could have significant benefits. Advocacy for change in this area by non-Indigenous allies, and increasing an Indigenous presence in leadership at the policy making level are what is needed here.* (Journal entry December 5, 2020)

Summarizing the learning from this contextual reality focusing on the influence of the health care system, the experience and conversations the women shared have demonstrated the dominance of biomedicine on the lives of Indigenous women living with HF. Examples included: being rushed, not listened too, and having no say in the agenda of a health care encounter; biomedical practices of medication and self-management being provided with no account of other determinants; the poor use of language; health care providers use of power and a lack of cultural safety; the challenges of managing health between both Western and Indigenous worldviews and lack of seeing Indigenous culture within Western health care systems; and access challenges from experiencing blatant racism and discrimination, distance and cost, and the challenges with jurisdictional funding in what and where services are provided for Indigenous Peoples. While this ongoing debate over jurisdictional responsibility, Indigenous Peoples continue to suffer syndemic issues from colonization (Gouldhawke, 2021).

Contextualized Realities: Moving Forward in a Good Way

Traditional knowledge and healing, and the need for intergenerational knowledge transfer has been an ongoing conversation for the last few decades (Redvers et al., 2019) and within this study it was clear that moving forward in a good way continues to challenge health care professional. Moving forward in a good way is a common Indigenous way of thinking, reflected in much of the scholarly work I read as a graduate student. Dell spoke of attending an Elder led workshop at the university when she said:

> I went to a couple of her medicine workshops at TRU [local university] and they were awesome. We actually learned how to put together salves and learned different kind of things that you can cleanse your blood and all that. I'm actually going, really leaning more towards that than actually taking medications that are going to make me sick. The community is hungry for all that knowledge, there's a minimum amount of people that know. We need to pass it on down the line.

Delwiese shared how with the passing of her mother she had lost knowledge of her communities' traditions, but went on to say she was learning from social media, when she spoke of a Facebook site where she learnt about toothpaste and traditional medicine. Margaret shared "I learnt from my grandmother, I remembered some, and some from my own research". As well as sharing where the women themselves gained knowledge of traditional practices, they shared how they themselves are passing this along the line, when Margaret said “I passed on to my kids, my daughter mostly”, and Dell shared how she is passing on knowledge when she spoke of “going to the mountains gathering medicine and fruit” with her grandchildren.

Moving forward in a good way requires the need for social supports and advocates. Sources of support were identified within the health authority, in their own communities and Nations, among family members, and from the women themselves supporting each other. Within the health authority most women shared of times when they had accessed the APN program themselves, or knew of someone who had. Dell said:

> The navigators are awesome. I think they do an awesome job at the hospital. For outpatients when they give you so many directions and things you have to do then they’re there to help you and guide you after the fact.

Marilyn shared how the nurses at the clinic could support and better prepare her ahead of her medical appointments when she said:

> If they gave me advance, like tell me a week before the appointment, and sit down and talk with me, go over the diagnosis and explain to me properly. That would have been nice, not just go in there and tell me how it is and that’s it.

In addition to better supports from the health authority, services within communities and Nations were viewed as a vital resource for wellness. Dell stated:

> I believe there should be follow up there too, like um, I’m not sure who can handle that, but on the reserve, we are again left in the dark, because we have a health center, the health center should have somebody to talk too.

Dell then further added “there should be help there from the band. To help families understand what the individual is going through, what the outcome will be, or may be, how they can help the whole community”. Margaret felt that health care providers within her community were not equipped to support her when she said:

> Even our offices on the reserve don’t know what I’m going through, or how hard it is. They don’t even bother to check what it’s about and understand why we are asking for help. I’d like information put together for our care givers, our council, those people who really don’t know what the native communities go through when they’re sick. So, they can understand that we need their help.

Services led by Indigenous Peoples themselves was viewed positively as Dell said:

> They should employ more Indigenous, to have Indigenous health care professionals would be awesome because you know they would be able to relate and understand where you’re coming from.

Some women spoke of the role families and the wider community plays in their overall health and wellness, being a crucial source of support. Times when poor health care experiences were shared, the resolution often involved a family member advocating for a change. As Delwiese shared, “my daughter really advocated because that’s harassment. I didn’t have that disease they thought I had”. Dell’s conversation around her hospitalization with Quincey had many references to her family advocating for her. While acknowledging the important role families have as supports, families are similarly challenged with the same lack of understanding as individual patients, when Margaret stated “families don’t really understand what you’re trying to tell them”. Supporting families and communities, not just the individual, would be in keeping with traditional beliefs of health and wellness, and if addressed would have a positive impact.

For example, Delwiese suggested “sharing with my husband and my daughter would be very helpful” and Dell shared the importance of “helping families understand what the individual is going through, what the outcome will be, how they can help.”

> While families were seen as sources of support for many of the women, for some, families were not able to support. Margaret shared “everybody’s families have lives of their own, if you rely on them, you’re not going to get all the help you really need”.

While Marilyn stated:

> I wish I had more support. I just got my kids and me and my husband. I can’t really rely on my family, because they have their own lives and their own problems. I don’t want to burden my family with it.

In addition to health care professionals, family, and communities providing support, the women themselves felt they had a role in supporting other women with similar challenges. Margaret shared that she:

> Looked online to see where there are groups I could attend to hear of the stories, or talk. I’m looking for people with the same issue or problem as me, cause at least I could share it with other people.

Margaret went on to say:

> Other people that get what we had will probably understand it more if it was put in a pamphlet or book or something, with us sharing our experience and putting it out there. I think it would help a lot of people. I’m glad I wrote my story, so I don’t know how this will go about being shared but putting in a format that women that get this kind of disease can understand. Going through our experiences and how we ourselves came to cope with it I guess would be nice for others to read.

Dell said:

> If we work together to understand living with heart challenges, we can pass this knowledge and awareness to others, it would be so helpful. We need continued support, to support each other.

Support group services were also seen as beneficial for supporting aspects of their lives beyond living with their heart challenge when Margaret said this would be “not for the medical parts”. Dell similarly said:

> We can support each other, go for walks, go for tea or coffee, and say, hey are you guys going through this and this? It doesn’t even have to be a sit down, can have a coffee and just shoot the breeze.

Summarizing the learnings within the context of moving forward in a good way, the women identify the need for traditional healing and Indigenous worldviews. The need for increasing an Indigenous presence within the health care system and within communities and Nations, and more services within their communities was noted. The women want to see their experiences and conversations shared with leaders and health care providers at all levels of both the health authority and within their communities. They want more support for families, more social support, and support from other sources when family are not available. They want to be able to support each other, and others living with similar challenges. The women’s suggestions for support group services following our learning circle led me to believe, *this may be my greatest accomplishment in this research journey thus far, providing an opportunity for these three women to gather and share stories and support each other in a way meaningful and relevant to them* (Journal entry August 11, 2020). I hope to create more opportunities for this in the future. As I later reflect on this entry, *I see how excited I am following the learning circle and* *acknowledge my personal benefits in how this made me feel. However, what was most significant here was the positive impact it had on the women themselves* (Journal entry December 5, 2020).

Chapter Summary

As our journey reaches the end of this chapter, I hope I provided thorough descriptions of the knowledge shared by the women involved in this research, the meaning I made from our conversations together, and the meaning co-created with the women themselves. Our knowledge sharing reasserted much of what was presented in the literature review earlier. The women provided suggestions for actions that would meet their needs for living well. In making meaning of the women's experiences and suggestions the lack of cultural safety in the health care system was apparent and subsequently efforts are needed to improve cultural safety. The women's experiences and suggestions also provide strategies to move forward in a good way so to tackle inequities and bridge the gap in health outcomes for Indigenous women with HF. The women's experiences framed in the contextual realities presented here will form the basis for the subsequent chapters where we consider the literature in discussing these findings, creating meaningful change, and identify the implications of our findings for changing nursing practice, policy, and future research.

Chapter Five

Discussion

The findings from this research journey lend support for what is already known concerning elements that support and limit wellness for Indigenous Peoples, the root causes of limiting factors, and actions to address inequities. However, the findings from the study also reduce the gaps in knowledge identified in Chapters One and Two, by expanding the knowledge base to include: a focus on the experience of a group of Indigenous women living with HF and accessing health services, suggestions for programs and services identified by Indigenous women themselves that meet their needs to achieve wellness while living with HF, and actions for health care providers that support these unique needs. In this chapter I discuss key issues that emerged during meaning making as described in Chapter Four. As we continue on this journey together, it is important to note that, given the complexity of the experience of being an Indigenous woman living with HF, issues raised in each set of contextual realities interact and intersect with each other, and cannot be completely separated in the discussion.

Living with Heart Failure: Grief, Stress, and Trauma

Many of the women in this research shared the death of family members, for some this was related to heart challenges, and for some, such loss included their children. Consideration for the impact of such loss and how grief affects the women’s ability to live well, and the wider impact upon family and communities emerged during meaning making. In addition to living with grief, all the women reported significant stressors, such as being removed from families, communities and Nations, long hospitalizations isolated from support networks, raising grandchildren, attending residential school, and the stress of living with and managing a diagnosis of HF. In making meaning of the women’s experiences of grief and stress, the influence of trauma emerged. Meaning making of the influence of trauma in the lives of Indigenous women with HF links to historical, intergenerational, and racial trauma as examples of the intermediate and distal determinants of health, in addition to personal day-to-day stresses (McGibbon, 2018).

Racial stress and trauma include the impact of the ongoing everyday psychological stress of living with racism, with every culturally unsafe interaction adding to the experience of racial trauma (Allan & Smylie, 2015; Dwyer et al., 2016; Fast & Collin-Vezina, 2019; Jackson et al., 2013; McGibbon, 2018). The influence of stress and racism and their interconnectedness cannot be overstated when considering the experience of Indigenous women with HF given what we know of the influence of stress on the development of cardiovascular disease as presented during the literature review (Jackson et al., 2013). Like many Indigenous women, the women in this research are managing their health and wellness while experiencing racism, and colonialism. These -isms directly link to stress and trauma while also being a barrier to accessing health care (Allan & Smylie, 2015). The multiple sources of stress and trauma for Indigenous women compounds both the impact of stress and trauma and the complexity of supporting those living with trauma (Diffey et al., 2019; Fast & Collin-Vezina, 2019).

The biomedical model is inadequate for addressing the impact of trauma on the health and wellbeing of Indigenous women, families, and communities (Purkey et al., 2018). TIC was introduced in the literature review but is not widely considered in the area of cardiovascular care, with little literature to guide health care professionals in ways to support those accessing services who may also be living with the impacts of trauma. To be trauma informed is to understand the whole person not as a victim, but understanding the consequences of living with a history of trauma (Bent Goodley, 2018; Purkey et al., 2018). TIC is best achieved with continuity of care providers, and sufficient time with providers for trusting relationships to develop which is often organizationally challenging in health care programs and services (Purkey et al., 2018).

While early work to introduce the notion of TIC has raised awareness of the significance of trauma on the lives of Indigenous Peoples, the concept itself has subsequently been criticized for having an individualistic focus similar to CDSM (Ginwright, 2018; Wilson & Richardson, 2020). TIC has been further criticized for focusing on treating the trauma rather than focusing on health and wellbeing, or the root causes for the trauma (Ginwright, 2018: Wilson & Richardson, 2020). Clark (2016) goes so far as to state the concept of trauma perpetuates colonization by suggesting those experiencing trauma require intervention and saving from the colonizers who caused the harm.

An alternative to TIC is the consideration of healing as an approach that privileges healing to be “as important” as curing (Sakallaris et al, 2015). Healing-centered approaches are holistic, and considers healing from a collective rather than individual stance with a focus on wellbeing (Ginwright, 2018; Wilson & Richardson, 2020). Healing-centered approaches require consideration of the root causes of trauma, thereby considering colonization, racism, oppression, and social justice. That is, the structural influences on the cause of the trauma and subsequent healing approaches (Ginwright, 2018). With such a foundation it is easy to see how healing approaches fit well with cultural safety, anti-racist, and anti-oppressive work. Healing-centered engagement privileges culture and identity (Ginwright, 2018; Wilson & Richardson, 2020). A focus on healing rather than trauma focuses on healing taking place within relationships and interpersonal environments at personal and organizational levels (Sakallaris et al., 2015). Healing-centered approaches, if coming from a strength-based approach, would focus on the human rights of Indigenous Peoples as articled in UNDRIP (2007) altering power imbalance, building trust and empowerment, and encouraging collaborative decision making (Lines et al., 2019; Unick et al., 2019).

Addressing the Influence of the Health Care System

During meaning making of the influence of the health care system, two key sub-themes emerged. The women's experiences of culturally unsafe care, and a lack of services within communities and Nations which created barriers in accessing care for Indigenous women.

Building Cultural Safety

All women in this research shared interactions in health care that they perceived to be culturally unsafe. As documented in detail earlier, Marilyn shared of being disrespected and made to feel like an alcoholic when she collapsed, Delwiese shared being treated like she had an infectious disease and isolated even when tests confirmed she did not, while Dell's experience with Quincey demonstrated multiple culturally unsafe interactions with a variety of health care professionals. The women shared examples of the dominance of the biomedical approach, where Indigenous worldviews of health and wellness were not valued, and where interactions were rushed, with poor communication. This is in keeping with similar work from Phillips-Beck at al. (2020).

The UNDRIP (2007), the TRC (2015), and a multitude of policies from key health care partners such as the British Columbia College of Nursing Professionals, the Canadian Nurses Association, the First Nations Health Authority, Interior Health Authority, and British Columbia Association of Aboriginal Friendship Centers provide structural and systemic level support for the provision of culturally safe care. Given so much policy to support culturally safe care, consideration must be given as to why the women involved in this research, like many Indigenous Peoples, continue to report culturally unsafe care. McGibbon (2018) links failings in cultural safety as one of the reasons for ongoing colonialism in the health care system that is harmful to Indigenous Peoples accessing care. Such failings in cultural safety reside not only within health care institutions, but within health care professional's education curriculum, and within professional licensing bodies.

Cultural safety is inclusive of allyship, anti-racist, and anti-oppressive health care, and is key in making meaningful change to redress disparities in outcomes for Indigenous women. The concept of cultural safety was discussed in the literature review, with one of the core components being to challenge power imbalances at the personal, professional, and institutional level (Cox & Taua, 2017). Tremblay et al. (2019) identify three types of cultural safety strategies that attempt to address such power imbalances: those which change the health care system environment, those which strengthen the presence of Indigenous Peoples in the workforce, and those which educate health care professionals. The women in the study spoke directly to the first two of these strategies, however, the women's interactions also warrant a discussion of cultural safety training.

Several of the women in this research suggested seeing Indigenous culture reflected in the health care education material provided in the HFC, and the clinic environment itself, would be a positive influencer of cultural safety. Seeing Indigenous culture reflected is in keeping with the second strategy for cultural safety identified by Tremblay et al. (2019); modifications to the health care environment. Some scholars acknowledge that Indigenous Peoples want to see traditional healing incorporated into the biomedical health care system (Howell et al., 2016; Redvers et al., 2019), and some of the women in this research shared their experiences, and the challenges of accessing traditional healing and using traditional medicine within the health care system. Turpel-Lafond (2020) also acknowledged a lack of consistent and meaningful integration of traditional Indigenous healing practices within health care in BC.

Accessing traditional healing within biomedical health care environments can have benefits to those receiving care by enhancing the meaningfulness and relevancy of care received, and can also be empowering for nurses (Bourque Bearskin, 2011). Incorporating Indigenous cultural protocol and worldviews presents logistical challenges for Western institutions grounded in a single focus of biomedicine (Greenwood et al., 2017), but must be addressed, with the inclusion of culturally appropriate spaces for ceremony, and increasing the visible presence of Indigenous culture (Greenwood & Lindsay, 2019; Turpel-Lafond, 2020). However, it is important to acknowledge that the inclusion of traditional beliefs and knowledge systems is not the work of non-Indigenous people working in the system, rather their role is to support Indigenous Peoples themselves in reclaiming traditional approaches to wellness, in strengthening Indigenous self-determination (Kennedy et al., 2020).

Many women in this research advocated for a need to increase the presence of Indigenous health care professionals, and specialized roles such as the APN. Such action has been widely supported to address inequities in health outcomes for Indigenous Peoples, (Allan & Smylie, 2015; Dwyer et al., 2016; NCCIH, 2019) and is the third intervention Tremblay et al. (2019) identified for building cultural safety. Increasing an Indigenous presence in the workforce needs to occur not just in health care, but within the education system and justice system, at all levels (McGibbon, 2018). Supporting Indigenous involvement in leadership and decision making where this presence is most influential is critical for creating health system change (Halseth & Murdock, 2020; Turpel-Lafond, 2020).

Cultural safety training is common practice throughout health care institutions as a strategy to educate health care professionals to improve their ability to provide effective culturally safe care. Di Angelo (2011) acknowledges that for some individuals, cultural safety training is the only time they experience a challenge to their cultural beliefs as the norm. Most trainings contain some kind of workshop to convey information about historical matters and belief system, but such workshops are generally not of sufficient time frame to absorb all the material presented and have little continuity after the fact. Training may therefore increase knowledge but with no opportunity for self-reflection, it does nothing to challenge attitudes and change behavior; failing to address white privilege, racism, and power imbalances at any level (Cox & Taua, 2017; DiAngelo, 2011; Jackson et al., 2013).

Cultural safety training has been criticized due to a focus on individual practices which suggests that individuals are the cause of discriminatory and racist practices, ignoring the institutional and systemic impacts on cultural safety and the determinants of health (Dwyer et al., 2016). Such an individual focus ignores the impact of workloads upon the provision of culturally safe care (Jackson et al., 2013; Rix et al., 2016). Structurally there are gaps between policies which address discrimination and the implementation of effective action (Dwyer et al., 2016). Some have argued the ongoing push for cultural safety training only serves financial objectives, and gives merely an impression of diversity and inclusivity (Shepherd, 2019). Turpel-Lafond (2020) acknowledged the inadequacies of cultural safety training to address racism in the context of BC, highlighting the San'Yas ICS training program, developed by the Provincial Health Services Authority in 2009 was not universally funded or offered, and was developed without the involvement of the communities and Nations in BC. Others argue that there is misunderstanding around the notion of treating everyone the same, confusing the concept of equality and equity

(Cox & Taua, 2017). Leadership and policy which fosters equity and an ani-racist stance is needed rather than a focus on being multicultural (Jackson et al., 2013).

Cultural safety training lacks any rigorous evidence base to support its implementation (Shepherd, 2019). Tremblay et al. (2019) suggest the lack of evidence is linked to the variety of terms and definitions used, and the range of implementation strategies. As we saw in the literature review, the notion of cultural competence is criticized as it focuses on different features of different groups without any attempt to address power, privilege, or racism which leads to non-Indigenous people essentializing culture and making assumptions about Indigenous Peoples (Dwyer et al., 2016; McGibbon, 2018). The term competence also assumes one can become competent, that there is an end point in the learning (Cox & Taua, 2017; Curtis et al., 2019).

A most dangerous critique of cultural safety training is that it actually worsens white privilege and oppression by creating a "shame and blame approach" with no time for self-reflection (Shepherd, 2019). In doing so the concept of white fragility is strengthened. Many authors have spoken of the anxiety non-Indigenous people experience when asked to contemplate discriminatory practices, as it involves "nice" nurses being involved in racism (McGibbon et al, 2014). Such racism anxiety can lead non-Indigenous people to feel defensive about such work (Dwyer et al., 2016). This silence or inaction however suggests support for oppressive practice and it is this inaction which needs to be addressed (DiAngelo, 2011; Hughes, 2018; McGibbon et al., 2014; McGibbon, 2018; Stout et al., 2021).

Allyship, "the process for white settlers to make visible their cultural and epistemic domination in health care" (McGibbon, 2018, p. 41), is at the center of cultural safety and decolonization, and involves recognizing white privilege, taking an anti-oppressive stance, and building relationships with those who are experiencing racism. To enact allyship, one needs to truly listen, and consider whose voices carry the most weight. When enacting allyship one needs to openly talk about privilege, be open to criticism, and accountable when mistakes are made (Jones et al., 2019; McGibbon, 2018). As I studied McGibbon's (2018) work I noted:

> *I was drawn to the seven-point continuum of white settler movement, and at this point in my journey feel quite comfortable to offer I see myself as being at point four. Point four involves recognizing racism, white settler privilege, and taking individual action for cultural safety, truth and reconciliation. To be publicly out about racism and white settler privilege. I hope my thesis work will move me toward point five; Educating self and community about racism, settler privilege, culture safety, truth and reconciliation, pairing racism with historical and current white settler benefits. As I strive to work for social justice in my nursing career, I may achieve point six; Initiating public collective truth-telling about ruling societal system that sustain racism, colonialism, white settler privileged and benefits of white supremacy and point seven; naming, dismantling and preventing ruling societal systems that create and sustain white settler privilege and supremacy and new forms of colonialism*. (Journal entry December 5, 2020)

Opportunities for individuals to safely examine their own white privilege, and work towards anti-racist and allyship goals are a good starting point (DiAngelo, 2011) but this needs to be done alongside similar efforts of the nursing profession and other health disciplines, while the profession advocates not just against racism but also the influence of unjust, inequitable determinants of health (Jackson et al., 2013; Jones et al., 2019; McGibbon, 2018; NCCIH, 2019; Smith, 2019). Nursing has developed within colonization striving for recognition as an academic discipline grounded in biomedicine, and this has perpetuated white privilege and ultimately stifled the ability of the profession itself to challenge the root causes of disparities (McGibbon, 2014). We have a duty as nurses to address the ongoing colonialism of nursing, and create change at service delivery, systemic, and structural levels with a social justice equity lens.

Funding is Harming Access

Several of the women in this research raised challenges with accessing health care, and this is well documented as a reason for inequities in health outcomes for Indigenous Peoples (NCCIH, 2019). Barriers to accessing health care for Indigenous Peoples living in rural and remote communities as well as those living in urban areas have been linked to appropriateness, affordability, availability, acceptability, and approachability of services (Halseth & Murdock, 2020). It was clear from meaning making of the experiences of the women in this research that, when discussing access challenges, we need to consider not just how health care is organized, but also how health care is funded for Indigenous Peoples. Health care system funding is complex and multijurisdictional, which contributes significantly to the inequity in availability of services (Allan & Smylie, 2015; Halseth & Murdock, 2020; NCCIH, 2019; Phillips-Beck et al., 2019; Webkamigad et al., 2020).

The Federal government continues to refuse to acknowledge funding health care for Indigenous Peoples as a treaty right, or human right (Gouldhawke, 2021; NCCIH, 2019). Disputes over responsibility and control leads to variability in funding which negatively impacts the abilities of communities and Nations to be self-governing in the health care services provided (Halseth & Murdock, 2020). The Transformative Change Accord (Government of BC, 2005) subsequently led to the creation of the FNHA in 2013. The FNHA assumed responsibility for federal programs for those living within communities and Nations that had been the responsibility of Health Canada, and the delivery of NIHB to all Indigenous Peoples residing in BC with “status”. NIHB includes dental care, vision care, medical supplies, and medical equipment not provided under provincial health insurance, and is currently provided in partnership with Pacific Blue Cross (FNHA, 2021). The FNHA goal is to support health and wellness for all Indigenous Peoples in BC, working to increase Indigenous representation and governance throughout the health care system. To date, full financial control for health and social services for Indigenous Peoples has not been given to the FNHA. With the other Canadian provincial and territorial governments continuing to have responsibility for the administration of NIHB and services within communities and Nations. The clearly documented variation in services available for; Indigenous Peoples living in urban centers and away from home (FNHA, 2021); that health care services within communities and Nations are not consistently funded, providing a varying level of programs and services throughout the province to those living within communities and Nations; and that services are only for those with “status”, excluding Metis and those without such “status” (Allan & Smylie, 2015) contributes to ongoing inequities for Indigenous Peoples (Phillips-Beck et al., 2019). Dell and Margaret shared examples which support such varied and inconsistent service within their own communities and Nations, and during meaning making this finding was linked to funding and organization at the structural level. The FNHA is a promising model for Indigenous health governance and supporting self-determination, and work is needed for changes at the structural level to further support the work of the FNHA and develop Indigenous health care legislation (Gouldhawke, 2021; Halseth & Murdock, 2020). Indigenously controlled health care delivery for Indigenous people would significantly improve the health and wellbeing of Indigenous Peoples (Dwyer et al., 2016).

Key Issues in Moving Forward in a Good Way

The women in this research shared examples of what is needed to move forward in a good way, and support the health and wellness needs of Indigenous women living with HF. In addition to actions that support wellness already discussed above, such as the inclusion of healing-informed approaches, addressing cultural safety, and the funding and organization of health care programs and services, the women identified the need for improved social supports, and the need to reclaim traditional knowledge systems. Meaning making also led to consideration of the process of creating meaningful change.

Improved Social Support Networks

The women shared the challenges and impacts upon daily life of living with the symptoms of HF, managing the many requests of health care providers to follow self-care guidelines and take prescription medications, and how symptoms influence the ability to perform usual social roles. Meaning making of this finding led to consideration of currently available social supports for women living with HF, identifying gaps in current service provisions, and actions for change to move forward in a good way. Consideration of the women's experience regarding available social supports is timely and provides further support for a recently published scoping review by Webkamigad et al. (2020) examining the health and social care needs of Indigenous older adults with chronic conditions (including heart disease) and their caregivers, which identified five themes echoing the contextual realities identified in this research: 1. Accessibility of health care services (financial impacts and geography, the need for local services, culturally relevant services, the provision of meaningful and relevant information, and the impact of negative treatment and poor communication); 2. Community capacity (the detrimental impact of having to relocate, community support networks, and building community capacity); 3. Social support networks (traditional and intergenerational support networks and education for caregivers); 4. Cultural values within the health care system (holistic approaches, traditional practices and cultural safety); and 5. Wellness based approaches (self-care, grief and social support, including supporting and sharing each with other).

The women identified the need for health care services within communities and Nations which support not just the individuals living with HF, but also their families, and the communities themselves. The women identified the use of support group services suggesting support groups should be locally led, not focused on the medical parts, but focused on living with and coping with health challenges from an Indigenous perspective, and utilize traditional knowledge. Such support groups for those living with HF, would enable the women themselves to support each other in ways meaningful to them. Diffey et al. (2019) examined heart health among Indigenous women, and promoted the use of support groups, acknowledging that such groups privilege storytelling as a traditional practice, and are healing to individuals, families, and communities.

Reclaiming Indigenous Knowledge Systems

Some of the women in this research shared the importance of traditional knowledge systems, and reclaiming traditional practices, including how they themselves are practicing intergenerational knowledge transfer. Many of the women spoke of passing on knowledge to their children and grandchildren, while some were reclaiming traditional knowledge for themselves by attending courses facilitated by Knowledge Holders and Elders, and accessing information online. Dell’s experience with her connection to the land through gardening, hunting, fishing, demonstrated her passion for building community by coming together.

Reclaiming traditional knowledge systems links to healing, and healing-informed approaches discussed earlier which some authors have linked to resiliency (Fast & Collin-Vezina, 2019). Resiliency is connected to current healing and to healing of past and future generations (Clark, 2016). Kirmayer et al. (2011) examined resiliency in the Roots of Resiliency project, and describe resiliency as “characteristics of individuals, families, communities, or larger social groups, and is manifested as positive outcomes in the face of historical and current stresses” (p. 85). Indigenous Peoples have been living with the impact of colonization for hundreds of years which demonstrates the resiliency of Indigenous Peoples (Allan & Smylie, 2015).

However, some have critiqued the concept of resiliency, as it comes from a colonial perspective shifting the focus away from Indigenous resistance to colonial domination, avoids creating solutions to the issues and hides systemic racism (Srivastava, 2021). Focusing on resistance of colonial domination and reconciliation may instead be the best way forward. Efforts to increase Indigenous governance and self-determination build community resistance, and is part of the reconciliation agenda. In terms of health and wellness, Indigenous governance would support the human rights of Indigenous Peoples to achieve the highest possible standard of health, and practice their cultural health and wellness beliefs and practices to the fullest extent as Articled in UNDRIP (2007). Resiliency and resistance are reflected in ongoing efforts to revitalize traditional practices, beliefs, and languages (Gone et al., 2019; Kirmayer et al., 2011), with efforts to revitalize Indigenous languages reportedly occurring in BC with financial support from DRIPA (2019). There needs to be government support for similar efforts to revitalize traditional healing practices, traditional relationships and roles, and intergenerational practices to support the wellbeing of Indigenous women living with HF (Diffey et al., 2019). Revitalizing Indigenous knowledge systems and reconciliation may counter the many human rights violations indigenous peoples have faced (UNDRIP, 2007)

Creating Meaningful Change

The women's conversations, particularly during the learning circle, and subsequent meaning making provided suggestions for action that support creating meaningful change in the health care system. These actions will be further outlined in the following chapter. The women's suggestions for change supports the work of Diffey et al. (2019) to address the heart health of Indigenous women in their research including: the need for relational approaches that consider Indigenous women's relationships to their ancestors, families, and communities, and which includes talking circles and storytelling, services which are healing informed, addressing power imbalances, and centering and privileging Indigenous worldviews.

During the learning circle, the women in the study had an opportunity to provide suggestions for action which inform creating meaningful change. How these suggestions would be put into practice, who would take on this work, and who would fund the actions they suggested were raised by the women as a concern in moving forward with actions. Creating change in the health care system is complex and multifaceted, involving many levels of power and responsibility and multiple professional disciplines. According to the work of Macleod et al. (2020) in the Northern Health region of BC, there is a limited evidence base as to the "how" of health care transformation and their work provides practical knowledge for ways individuals and organizations can work together across multiple jurisdictions for health care transformation. Despite structural and systemic policy to support improvements in service delivery to better meet the needs of Indigenous Peoples, change is slow. Such slow change is partially the result of systemic and structural barriers within our social institutions and organizations that prohibit enacting policy recommendations to the fullest extent. In terms of the health care system, McGibbon (2018) identifies these barriers as: a lack of political support for change, a lack of accountability within the system, provincially funded systems, and systemic factors which make questioning power and the lack of accountability difficult for those who challenge the status quo. To combat the influence of these barriers, the twenty-four recommendations set out in the report of Turpel-Lafond (2020) provide a way forward to address Indigenous-specific racism.

Creating change in service delivery models, particularly working towards Indigenous models of health and increasing Indigenous governance over health care services requires partnership and collaboration, with the focus being people within communities (Halseth & Murdock, 2020; Macleod et al., 2019). Identifying the right people, the need for purposeful conversations which respects multiple views and using language that reflects intention and action are needed. Due to the diversity of Indigenous communities, no one approach exists, but we know the important guiding principles for Indigenous models of service delivery: a coordinated multi-level approach, supported by structural policy that addresses the barriers identified with the current jurisdictional funding, Indigenous leadership, the incorporation of actions that address determinants of health, a culturally safe and appropriately skilled workforce, quality improvement measures and tools for data collection that are appropriate and meet the needs of the specific community, and subsequently services which focusing on local needs, local initiatives, and local capacity so service models are grounded in local contexts and knowledge systems (Halseth & Murdock 2020).

Chapter Summary

Despite the complex intertwining of the key issues identified in meaning making and presented in the findings of the three contextualized realities of the women in this study, this chapter provides a discussion on the important topics when considering the experience of Indigenous women living with HF, and the implications for creating meaningful change in health care programs and services. This chapter has focused on grief, stress, and trauma; building cultural safety; the impact of jurisdictional funding; increasing social support networks; creating meaningful change; and reclaiming traditional knowledge. As I continue my journey in the last chapter, I build on literature presented during the literature review and discussed here, with consideration of the women’s experience of living with HF, to highlight how this information is related to implications for practice and policy change at a service delivery, systemic, and structural level, as well as for future research.

Chapter Six

Implications for Creating Health System Change and Concluding Thoughts

In bringing this work to a close in this final chapter, I present how the findings of this research can guide action for changing practice and policy to improve the experience of Indigenous women living with HF, utilizing Greenwood's (2019) framework (see Appendix L). In listening to the women's suggestions in the learning circle, and by examining the findings at the service delivery, systemic, and structural levels, actions for creating culturally safe programs, services, and nursing practice will be proposed in this chapter. Knowledge Translation (KT) and knowledge mobilization, understood as knowledge sharing strategies by the women themselves, will be identified. In this research KT includes how the women themselves wish to share their stories and suggestion for action, and how as a non-Indigenous settler nurse-researcher, I can share the knowledge co-created with the women. Acknowledgement of the limitations of this research and areas for further study will follow. I conclude with a summary of the findings from my personal learnings, and describe how I have developed my ability to use a decolonizing lens and moved forward with the goal of being seen by Indigenous Peoples as a settler accomplice and co-resistor, considering the initial research questions.

Implications for Changing Practice and Policy

Colonization, unjust distribution of the determinants of health, racism, and white privilege continue to negatively impact the health of Indigenous Peoples (Jones et al., 2019). Addressing these factors while creating opportunities to increase Indigenous self-determination and leadership, and while supporting reclamation of Indigenous knowledge and practices, are needed to create meaningful and lasting change in the lives of Indigenous Peoples (Oetzel et al., 2017; Turpel-Lafond, 2020). The women's conversations clearly identified the proximal determinants (employment, income, health behaviors, and food security) and service delivery factors which influenced their daily lives and their ability to live well. As themes were identified and making meaning progressed, the underlying influence of systemic and structural factors, of the intertwining of intermediate determinants (the health care system, how care is organized, biomedicine) and distal determinants of health (colonization, racism, and discrimination) on the service delivery component was striking (Webkamigad et al., 2020).

Service Delivery Level

The women in this research identified important actions at the individual provider and service delivery level to support them living well with HF. The women identified the need for health care services which center and support Indigenous knowledge, beliefs, and practices. The women identified the need for interactions with health care professionals where they feel informed and empowered, and where their beliefs and practices are considered. The responsibility of each individual health care provider for achieving cultural safety in each interaction cannot be overstated.

The women identified the need for services within their own communities and Nations, and for services which are led by Indigenous Peoples themselves. Improved social supports which includes support for families and communities were also important factors for the women in this research. The women identified a need to share their experiences with those facing similar health challenges, with a handout or other written document that health care professionals can give to patients that shares their experiences so patients do not feel so alone. The women suggested creation of a document with their stories that included traditional recipes, or recipes that are easy to make for those living with the daily struggles of the symptoms that accompany heart challenges.

The women suggested Indigenous specific content be included in education material, for example within the “Living with HF” binder, making resources more meaningful and relevant to Indigenous women. The women suggested that health care professionals were not fully equipped with the knowledge and tools to support them or their families. To overcome this, the women suggested creating a document that shares their experience with health care professionals so providers better understand the experiences of living with HF and ultimately, be able to provide appropriate support for them by better understanding their own unconscious bias and its influence on care.

The women’s experiences highlighted practice implications in regards to the impact of trauma and need for efforts to support healing for Indigenous Healing-informed approaches are beneficial for supporting the achievement of wellness not just within mental health services but within all areas of service delivery, and efforts to integrate healing-informed approaches into the HFC would enhance the support Indigenous women receive when they access this service.

Equity orientated health care (EOHC) has been identified by Ford-Gilboe et al. (2018) as a service delivery model that improves health outcomes for Indigenous Peoples and their work provides overarching support for the actions suggested by the women in this research. EOHC includes services and service providers that are culturally safe, healing-informed, and contextually tailored. EOHC is defined as:

> An approach that aims to reduce the effects of structural inequities, including the inequitable distribution of the determinants of health, that sustains health inequities; the impact of multiple and intersecting forms of racism, discrimination, and stigma on people’s access to services and their experiences of care; and the frequent mismatch

> between dominant approaches to care and the needs of people who are most affected by health and social inequities. (Ford-Gilboe et al., 2018, pp. 639-40)

Such an approach embedded in the care of Indigenous women with HF at the service delivery level would be a step towards addressing the inequities in outcomes Indigenous women are currently living with as colonial attitudes and practices would be challenged, Indigenous worldviews and beliefs would be centered, and self-determination would be increased.

Recommendations/Actions:

- Centre Indigenous beliefs and practices at the service delivery level.
  - Add Indigenous specific content to the HF education material given to those who access the HFC.
  - Support Indigenous women who access Western health care services to utilize traditional healing alongside Western treatments, if they choose.
- Provide better social supports for individuals, families, and communities.
  - Create a mechanism for sharing the women's stories with other Indigenous women living with HF.
  - Create support groups within communities and Nations, which are locally led, and not focused on the medical parts of living with HF.
  - Create information material and support services related to living with HF, for families and communities.
- Incorporate healing informed approaches into individual nursing practice and the service delivery of all programs and services including HFCs.
- Improve cultural safety of individual nurses, other health care providers, and the HFC environment.

  - Support participation of all nurses and other health care providers in cultural safety training which examines Indigenous-specific racism, white privilege, and building allyship.
  - Share the experience and stories of the women in this research with health care professionals who provide care to Indigenous women with HF.
  - Make modifications to the HF clinic environment so it is more welcoming to Indigenous women.
- Champion equity orientated service delivery. Promote nurses and other health care providers' ability to provide individually tailored health care interactions, deemed by those accessing them to be culturally safe, and healing informed.

Systemic Level

Meeting the needs of Indigenous women living with HF at the service delivery level requires focused efforts at the systemic level. Improving services within the health care system includes consideration of access to services which is influenced by socioeconomic factors such as cost and distance; challenging the unjust distribution of the determinants of health; and improving access by providing services and programs that are viewed by Indigenous Peoples themselves to be culturally safe, anti-racist, and anti-oppressive (NCCIH, 2019).

The women identified the need to increase the presence of Indigenous Peoples in the workforce. The need to build the capacity of Indigenous health care professionals and APNs is widely supported in the literature (NCCIH, 2019). Such action requires structural and systemic support; in the education system with increased funding for seats in health care program training for Indigenous Peoples (CASN, 2020); and within the health care system with increased funding for APN positions to enable extension to out-patient services, not just acute care.

Financial investment is needed to support services within communities and Nations, with such services centered with Indigenous leadership setting priorities for services to meet the unique needs of each community. Western institutions and organizations need to create more opportunities to involve Indigenous Peoples in decision making, and opportunities that foster partnerships and collaboration with the communities and Nations they serve, and be a visible ally in efforts to enhance Indigenous governance and self-determination. Systemic allyship would involve institutions and organizations having in place and fully enacting policy to end racism and discrimination, and support cultural safety. Organizations would foster a “speak-up” culture (Stout et al., 2021). Institutions and organizations would collaborate with Indigenous Peoples, communities and Nations to identify and meet the needs of Indigenous Peoples as identified by themselves (Rogers et al., 2019).

All social institutions must all address systemic racism and cultural safety. Resources are required for cultural safety education, but this education needs to address much more than knowledge of history and belief systems. Education must focus on Indigenous determinants of health, racism and white privilege, and becoming anti-oppressive allies. The findings from this research journey are coming at a time when systemic racism in the health care system of BC has been publicly exposed in the report of Mary Ellen Turpel-Lafond (2020). Turpel-Lafond’s (2020) recommendations mirror many of the implications for practice identified in this research, and are important actions for systemic level changes.

Turpel-Lafond’s (2020) recommendations which are most relevant to this research’s findings and systemic level change include: recommendations eight and nine which focus on measuring cultural safety so to assess what change is occurring, recommendation ten which supports more culturally appropriate spaces for Indigenous Peoples within the health care system, recommendation eleven which aims to foster allyship and anti-oppressive work, acknowledging what was discussed in the prior chapter concerning silence and inaction, by advocating for a “speak-up” culture, recommendation sixteen which emphasizes the need to focus on the unique needs of Indigenous women, recommendation eighteen which supports an increase in Indigenous seats within health care curricular, and finally, recommendation twenty that lends support for interactions to be more trauma informed.

Systemically, findings from this research need to reach the appropriate teams and decision makers within the health authority and within communities and Nations, to support the changes and actions suggested at the service delivery level. Such action includes written reports and presentations to; IH leadership, (Interior Region First Nations Health and Wellness Advisory Committee, Partnership Accord Leadership Table, IH regional cardiac program, RIH leadership team); to the FNHA; to councils within communities and Nations; and community health directors.

Recommendations/Actions:

- Identify institutional barriers to achieving cultural safe care for Indigenous women with HF and strategies to address these.
- Create organizational support for principles of EOHC.
- Provide a written report of research findings and suggested actions to appropriate decision-making tables to influence funding priorities:
    - Funding to develop and implement support groups within communities and Nations.
    - Funding to develop Indigenous specific content in education material which is meaningful and relevant to the unique needs of each community.

  - Funding for increased APN support throughout the health care system, linking into communities and Nations.
  - Funding for more seats for Indigenous Peoples in health care profession education.

Structural Level

At a structural level, international, federal, provincial, and municipal level policy reaffirm what the women in this study reported as priorities at the service delivery, and systemic level to support the health and wellbeing of Indigenous women living with HF. Despite such a wealth of structural support identifying and addressing inequities in outcomes for Indigenous Peoples, full implementation of such policy is not occurring. Governments and top-level leaders need to lead the way and set the example for a system-wide approach that addresses racism, and cultural safety, and which tackles the unjust inequitable distribution of determinants of health. Funding must be sufficient to enact the policies and actions identified to create change. Non-Indigenous people in positions of power must use this privilege for social justice to fully enact policy, in supporting Indigenous Peoples themselves in opportunities to create meaningful change and move forward in a good way.

Turpel-Lafond (2020) stresses the importance of political support by making such provision the first recommendation in her report states the Government must apologize for the Indigenous specific racism that is occurring throughout the health care system and make a system-wide approach to addressing it a priority. The Declaration on the Rights of Indigenous Peoples Act (DRIPA) (Government of BC, 2019) is a step in the right direction, by providing political support for change. DRIPA (2019) included Indigenous Peoples and Indigenous governing bodies, and in the first annual report; *DRIPA 2019/20 Annual Report*, state making some strides into the determinants of health at the structural level, with housing, justice, and education being part of the action plan (Government of BC, 2020). All health leaders must advocate for Turpel-Lafond's (2020) recommendations to be implemented, in particular, encouraging the Federal Government and national health organizations to do similar work, and take similar action.

Structural support for increasing Indigenous self-determination, for programs and services based on Indigenous worldviews and practices, for greater attention to Indigenous specific determinants of health, and opportunities to strengthen Indigenous governance are needed (Downey, 2020; McGibbon, 2018). Recommendations two and three in Turpel-Lafond's (2020) report are a step towards this, identifying the need for a BC Indigenous health officer. Structural support for increasing Indigenous governance of health care, such as increasing funding to FNHA, to support the FNHA in identifying and controlling health care for Indigenous Peoples that meet their needs as identified by Indigenous Peoples themselves. Structural support for measuring and reporting adherence to implementing cultural safety is not yet in place but was recognized as a needed action by Turpel-Lafond (2020).

Recommendations/Action:

- Advocate for government and high-level leadership support for organizations and institutions to fully enact policy which tackle Indigenous specific racism, discrimination, and the unjust distribution of determinants of health.
- Advocate for federal and provincial support for opportunities to support Indigenous self-determination and self-governance.

- Accountability measures are needed to assess compliance with cultural safety. This could be achieved through accreditation processes, and through health care professional regulatory bodies.

Knowledge Translation and Mobilization

The women in this research made suggestions and recommendations for actions and changes to support the health and wellbeing of Indigenous women living with HF. As co-creators of the knowledge shared the women themselves are vital to relevant and meaningful KT; that is how the actions are translated into health care practice and policy change, and how their recommendations are shared with their communities and Nations. The initial goal of this research was to have Indigenous women themselves identify what they need to live well with HF, including programs and services, and barriers to achieving wellness. Centering the voices of Indigenous women was the reason IRM was chosen as the methodological foundation and why the role of the women in this final phase of the research is vitally important. KT is an important component for creating meaningful change at the service delivery, systemic, and structural level as the mechanism for sharing the actions and recommendations outlined above (Cooper & Dridger, 2018). All KT approaches will consider the literacy level of the target population, acknowledge the research co-creators, and if they choose, involve the women themselves.

Knowledge Translation and Mobilization Actions:

- Create a condensed report to share the key findings with decision-makers as identified above.
  - Knowledge sharing report to include the women’s recommendations;
    - Create appropriate materials within the HF binder.

    - Create a document where the women can share their experiences with other Indigenous women living with HF.
    - Create a document targeted to health care professionals and members of their communities.
    - Advocate for local support groups.
- Present the condensed report to relevant health care leadership teams with the women themselves invited to participate in these presentations.
- Share the findings in academic literature and present at relevant conferences, with the women themselves being invited to participate in publishing and presenting.

By highlighting that members of Indigenous communities, in particular Indigenous women within the interior of BC, have unique health and wellness needs when living with a chronic condition such as HF, culturally safe, healing informed, individually tailored, supportive health care services can be developed, in partnership with the women and their communities.

Limitations

The design of this research collected individual conversations followed by one single learning circle at the end. Utilizing an iterative circle design would have allowed for more time and potentially deeper sharing, as the women would have developed relationships with each other and myself. Further circles would have allowed for more time to be able to explores topics more fully. Finally, this research only attempted to explore the experiences of Indigenous women who accessed one HFC in the Interior region of BC, providing local context but many Indigenous Peoples access this service, from a variety of communities and Nations, and their voices also need to be heard. While COVID-19 presented logistical challenges to knowledge gathering and extended the time frame of knowledge sharing beyond what was initially planned, the accommodations made due to COVID-19 may have not impacted the findings. It is important to recognize these stories although similar in experiences should not be generalizable to all Indigenous women living with HF.

Future Research

Acknowledging the limitations set out above provides opportunities to identify future research in this area. The knowledge base for Indigenous women living well with HF could be extended by further research to understand the beliefs, practices, and experiences of those working within the system from a cultural safety lens, alongside the experience of those receiving care. Similar research with other health authorities across BC and other provinces, and with those living with HF who have not accessed standard biomedical treatment approaches, would broaden the knowledge base, adding more local context unique to each community and Nation. As would the inclusion of the experience of families and communities.

From the discussion of trauma and the need for social justice a healing-informed approach, and research in the area of healing-informed approaches within chronic disease health care services is needed to inform the utilization of this approach within this area of health care. The experience of the women involved in this research supports Diffey et al. (2019) who state there is a need for further research to understand the cultural and traditional contexts of heart health for Indigenous women, and focusing not on the typical risk factors for heart challenges but on the connection of such risk factors to colonization.

Best practice guidelines used throughout the health care system continue to serve as colonial practices by labelling and focusing on individuals, and on the disease or lifestyle factors, rather than addressing the underlying structural influencers of wellness (Clark, 2018; McGibbon, 2018). We know the biomedical model contributes to harming Indigenous Peoples yet we continue to force care from this perspective, even with structural policy identifying the need for a different approach (Phillips-Beck et al., 2019). In addition to addressing the underlying influencers of wellness, acknowledging the challenge with biomedicines best practice guidelines lends support for future research that builds an evidence base that is specific to Indigenous people's needs, priorities, and knowledge system, which includes Elders, communities, and each unique Nations context (Rogers et al., 2019).

The TRC (2015) Call to Action nineteen; measuring and reporting outcomes to identify and close gaps in health inequities, highlights the need for appropriate reporting and measuring, yet programs and services are not only designed around but also evaluated from the dominant Western perspective, even when provided to Indigenous Peoples. More research grounded in the principles of IRM is needed to support the development of tools and subsequent collection of more appropriate and relevant data (Rogers et al., 2019; Smylie & Firestone, 2015). Action is needed to develop culturally relevant and appropriate quality improvement and data collection tools to measure successes, as is increased Indigenous leadership in data collection and management.

Concluding Thoughts

This final section will present a concluding summary of my personal insight regarding professional practice, knowledge sharing, and recommendations for action. I include highlights of my personal learnings as I strive to decolonize myself and take personal action moving forward as a clinical practitioner to support the resistance and resurgence of Indigenous Peoples knowledge systems and understanding of relational practice. The section ends with my final thoughts.

Concluding Summary

This research created an opportunity to address gaps identified in the knowledge base when considering the health and wellbeing of Indigenous women living with a diagnosis of HF. Using IRM centered the voices of Indigenous women themselves, situating the women as co-creators of the knowledge shared. The women's experiences, stories, and conversations were the foundation for the recommendations and actions identified at the service delivery, systemic, and structural level, to create culturally safe, meaningful change in the health care system, and nursing practice, which can start to redress the inequities in outcomes for Indigenous Peoples, and move forward in a good way.

Supporting Indigenous women living with HF at the service delivery level led to actionable indicators for nursing practice and the health care system concerning; the need for holistic approaches, which center Indigenous beliefs, and practices; incorporation of healing informed approaches; improving cultural safety by acknowledging white privilege and addressing power imbalances, and increasing the presence of Indigenous Peoples in the health care workforce; improving social supports with services that support individuals, families, and communities, including the need for support groups; and creation and implementation of meaningful and relevant health education material.

Systemic and structural level changes were identified to support the service delivery level changes including; organizational level policy and funding supporting service level change, including actions and recommendations which address racism and cultural safety; funding for Indigenous Peoples for access to health care education programs; building Indigenous leadership to enhance self-determination and decision making, including efforts to address Indigenous health governance and the challenges of multijurisdictional funding for health care; creation of opportunities to develop partnerships and collaborations with communities and Nations; and policy and funding which address the unjust distribution of the determinants of health.

Researcher's Personal Learnings

Although I endeavored to thread my personal thoughts and reflections throughout this thesis, I now take a moment to review and highlight the key learnings for myself as a white settler nurse striving to become a settler accomplice, co-resistor, to address the health disparities of Indigenous Peoples, and the work needed for meaningful change to occur within the health care system. A summarized version of my learnings can be seen in my personal concept map (see Appendix J), where I separated my personal learnings into two main threads; learnings related to the research process, and learnings related to the research questions and the experience of Indigenous women living with HF.

Initially, I built my cultural competency by enhancing my knowledge of Indigenous ways of knowing and being, of Indigenous beliefs of health and wellness that are different to my worldview, and of IRM and conversational research methods. Through reflexive writing, peer support and mentoring, and ongoing learning about allyship, white privilege, and decolonization, I am moving beyond this "competence" to cultural safety, as I continue building allyship, working towards becoming a settler accomplice and co resistor. For me building allyship means being vocal of my learnings about white privileged and advocating for others to be critically self-reflexive in identifying their own power and privilege to counter colonial attitudes (Hughes, 2018). It means using my position within the health care system to advocate for fully enacting policies and practices that end racism and discrimination. It means ongoing work to continue to build relationships and collaborative partnerships with Indigenous Peoples, communities and Nations, to center Indigenous knowledge systems, Indigenous concerns and voices, increasing self-governance while striving for social justice (Downey, 2020). Even with the best of intentions, many of my early journal entries demonstrated cultural competence that led to an essentializing of culture, and making assumptions. Through examining my unconscious bias rooted in my beliefs, values, and assumptions, by questioning my motivations and why I made meaning the way I did, whilst developing an understanding of the concepts of whiteness, white fragility and white privilege I was able to move forward and work more from a decolonizing lens.

My personal reflections demonstrated the self-doubt that comes from doing this work, and created a space for vulnerability which ultimately contributed to great personal growth and development. I was constantly worried I was going to make an error with cultural protocol and offend somebody. The Knowledge Holders that supported me during the study provided immense guidance and encouragement, collaborating with me and the thesis committee. I am thankful for other scholars that had shared their work as non-Indigenous people working alongside Indigenous Peoples, as reading their work was often a source of support, and ongoing encouragement.

The women themselves provided encouragement. Delwiese shared how “talking to you is therapy for me because you understand the heart and that’s therapy in itself for me” [referring to our knowledge sharing conversation]. Dell shared with me that she was reluctant to participate in the research when first asked, but subsequently glad she had done so due to the way I conducted myself. I remember talking to the women about wanting to change the language in their stories when they themselves referred to home Nations and communities as reserves and I asked if I could change this to communities and Nations because I did not want them to feel they needed to conform to the impacts of the government and colonization in identifying their home lands as reserves, I was hoping to challenge the status quo. When I mentioned this, the women reaction suggested they were shocked I would suggest this, but glad to follow my lead and have this language in their conversation. I hope this is a step in the right direction.

Throughout the research process I have been able to consider my social location and personal way of being. When I listened to the conversations and made meaning I continued to examine how my social locations of daughter, wife, mother, and granddaughter was influencing my thought process and learnings. My social location of being a woman and the benefits of being a woman was important as I worked alongside these women, and I was mindful that even though we shared in being women I was still advantaged by my whiteness.

When I think of myself as a nurse, I was horrified to hear the women share experiences of racism and marginalization, yet I have spent a decade implementing CDSM models of care with little thought for how relevant this is to those I serve, with little question of the dominance of biomedicine and the power health professionals have. As I acknowledged in Chapter One when I spoke of the benevolent peace maker myth, I have spent my nursing career blindly following colonial practices with no real thought of racism or white privilege, unknowingly participating in the ongoing root cause of inequity due to silence and inaction.

I had taken so many things for granted before I was gifted this opportunity to reflect and be critical of my thoughts and values. In acknowledging what I had taken for granted I was able to take that a step further beyond gratitude to frustration for the inequitable distribution of the determinants of health, and it was this step that really helped with identifying my white privilege and the role it has played in my life so far, and serves as the foundation for future advocacy and social justice efforts in addressing Indigenous health as a human right.

In the early stages of knowledge sharing, I was experiencing some internal torment about trying to separate my roles of nurse and student researcher. That dominant worldview of a researcher's influence being separate so as to not hinder rigor was deeply ingrained in me. Following some excellent peer debriefing I came to realize the benefits of my role as nurse-researcher, especially in my relationships with the women involved. Listening more deeply is a skill I have practiced and improved upon throughout this journey. I love talking, and am used to being in the position of power, so it was hard for me to sit and be quiet and just listen to the conversations. Sometimes, in trying to achieve this I went too far, and was not conversational enough. I would ask my prompting question, listen to the answer and then when the woman involved stopped talking, I would ask my next question. It was hard to not be interview-like, but I got better at this as the journey continued. Reviewing the transcripts for the latter conversations I was more empathetically responding to the difficult experiences the women were sharing.

As well as listening, this experience also highlighted the impact of how I personally ask questions, and this was a significant learning for me that will continue to have positive benefits every day. Statements I thought were innocent comments, could have been interpreted as detrimental. Something as simple as when I said to Della, I should check the microphone because your voice is quiet and how without meaning to, I could have offended her, implying that quietness was bad. The way as nurses we ask questions, especially the use of "are you okay?" was a particularly significant learning for me.

One of my greatest learnings from my conversations with the six women I was blessed to spend time with, and my subsequent meaning making involves the concept of cultural safety. It was striking to me how ineffective the cultural safety training I had completed has been compared to this journey and the learnings from these six women. I found I was frequently questioning the professional socialization of nurses, and how this is contributing to the ongoing poor experiences Indigenous Peoples are reporting in the health care system. Cultural safety education and experiences that force non-Indigenous people to consider racism, white privilege and their role in what is needed to bridge the gap in health inequities for Indigenous Peoples. This finding comes at a time when racism in the health care system is in the spot light so an opportune time to share these findings and continue to vocalize and pursue this agenda as a upstander to calling out incidents of racism and discrimination.

As I shared in my reflexive journal on September 5, 2020, this research journey has been *the most effective means of cultural safety training I have had the opportunity to be a part of*. Creating opportunities for other health care professionals to learn from Indigenous Peoples themselves, as I have done so here, is vital. Providing an environment for the women themselves to share and support each other, and having the woman themselves be co-creators of the actions are significant for me in moving forward in a good way, and meeting the goals of this research. I hope this inspires other to do the same.

Final Thoughts

I am humbled by this experience and what I have learnt about myself. Doing this work has at times been emotionally exhausting, but this is nothing compared to the experience of colonialism and the daily impact of the inequitable access to determinants of health that influence the lives of many Indigenous Peoples. The effort and discomfort are needed if non-Indigenous Peoples are to mitigate the ongoing impact of colonial practices and move forward in a good way. I borrow this philosophy expressed by Indigenous scholars, who are trying to do the same within the colonial institutions that continues to erase authentic and diverse perspectives. Writing my thesis has been a journey of self-reflection and decolonization as I reflected on what

I initially wrote and then rewrote. I hope my journey becomes a springboard for others to create change in themselves and their work environments, which ultimately supports changes at the systemic and structural levels, thereby having a meaningful impact on the lives of Indigenous Peoples today and for future generations.

As was shown in my personal learnings, even small changes in our daily lives can have an impact and this record of my journey is intended to inspire other non-Indigenous people and specifically nurses to take a more active role in holding up social justice, working towards becoming a settler accomplice and co-resistor. This starts with small steps such as saying hello in Secwepemcstin, and land acknowledgements, role modeling for others to do the same. It means deeply listening to Indigenous Peoples. Becoming an accomplice means to have courage and use my voice to share this journey and my personal learnings, with individual health care practitioners and decision-makers and leaders, to inspire others and encourage others to ask critical questions of their own beliefs, attitudes, and motivations, which will challenge racism and colonialism in the health care system. It also means looking for opportunities to partner with communities and Nations to support implementation of the women's actions which will strengthen Indigenous self-determination and social justice. The more individuals who take on allyship work, the larger presence allies will have in Western institutions, which will support Indigenous Peoples within communities and Nations to achieve the priorities set by themselves, for themselves. My call to action, from one non-Indigenous nurse to another, is to request that you look within yourself to acknowledge your own white privilege and biases, as you begin to dismantle racism. This point of view requires that you become vulnerable, challenge defensiveness, accept there are different worldviews and ways to do things and be ok with the discomfort of this (Okun, 2013). As I noted in Chapter One, my hope was to co-create knowledge that begins to redress the health disparities that exists for Indigenous Peoples. I believe that sharing the results of this study has the potential to support health system transformation to improve the experiences of Indigenous women living with HF.

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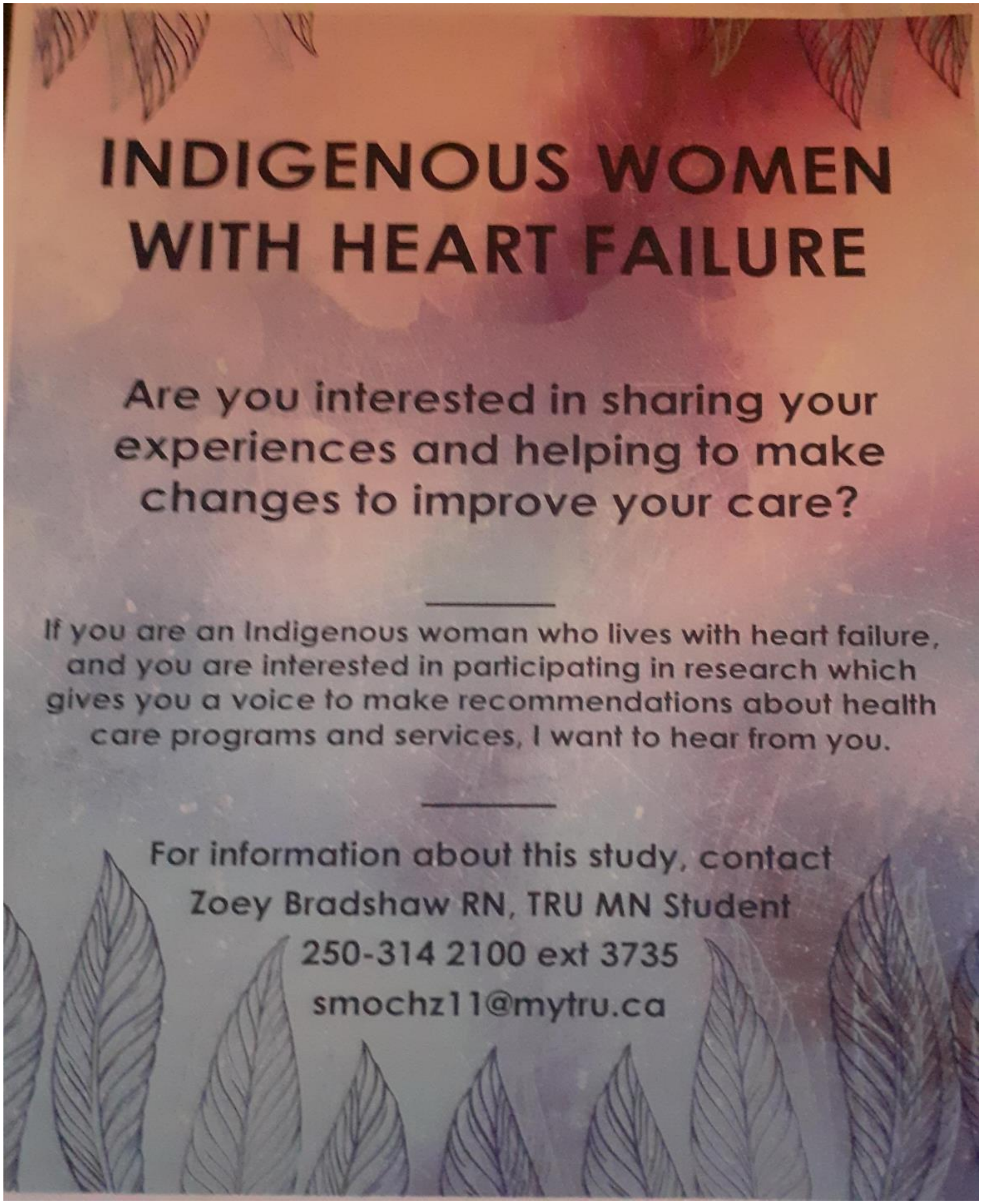
Appendix A

Recruitment Poster



INDIGENOUS WOMEN WITH HEART FAILURE

Are you interested in sharing your experiences and helping to make changes to improve your care?

If you are an Indigenous woman who lives with heart failure, and you are interested in participating in research which gives you a voice to make recommendations about health care programs and services, I want to hear from you.

For information about this study, contact
Zoey Bradshaw RN, TRU MN Student
250-314 2100 ext 3735
smochz11@mytru.ca

Appendix B

Third Party Recruitment Script

Research Project Title: Indigenous Women with Heart Failure in The Interior of British Columbia. Implications for Creating Service Delivery Change

Script for recruiting participants in the Heart Function Clinic during the clinic visit

RN or Cardiologist present in the visit.

There is a research project being carried out with Indigenous women with Heart Failure. It is being done by Zoey Bradshaw, a RN and a Master of Nursing student at the Thompson Rivers University School of Nursing. Do you self-identify as Indigenous?

If the woman says yes - The purpose of the study is to understand what it is like for you to live with heart failure, what your experience of health care related to heart failure has been like, and what programs and services you would like to see provided for Indigenous women with Heart Failure. Would you be interested in speaking with the researcher for more information about the study?

If yes, hand them the Consent to Contact Form to read and sign.

Appendix C

Consent to Contact Form

Research Project Title: Indigenous Women with Heart Failure in The Interior of British Columbia. Implications for Creating Service Delivery Change

Zoey Bradshaw is a Registered Nurse and a Master of Nursing student in the Thompson Rivers University School of Nursing. She is completing a research study about the experiences of Indigenous women living with heart failure

- Many Indigenous women are living with heart failure.
- This study will help with understanding what it is like for you as an Indigenous woman to live with heart failure, how you manage living with it, and what your experience has been with services you have received related to your heart failure.
- Learning about your experiences is important for making recommendations for future programs and services that can better meet the needs of Indigenous women living with heart failure.

You are being approached for this study as you may be eligible to participate. If you are interested in hearing more about being a participant in this study, please complete this form and the researcher will contact you directly.

If you do not agree to be contacted, there will be no impact on the care you receive at this clinic.

- Your signature indicates that you consent to being contacted by the researcher to discuss participating in this study.

____
Participant Name

____
Participant Signature Date

____
Participant telephone

____
Email Address (if you would like to be contacted this way)

Appendix D

Consent Form

Research Project Title: Indigenous Women with Heart Failure in The Interior of British Columbia. Implications for Creating Service Delivery Change.

I. STUDY TEAM

Who is conducting the study?

Principal Investigator:

Dr. Bonnie Fournier, Thompson Rivers University, bofournier@tru.ca, 250-318-738.

Graduate Student Investigator:

Zoey Bradshaw, Masters of Nursing Graduate Student, Thompson Rivers University, smochz11@mytru.ca. Phone 250-314-2100, ext. 3735

Thesis Co-Supervisor:

Star Mahara, Thompson Rivers University. smahara@tru.ca, 250-828-5441.

II. SPONSOR

Who is funding this study?

- The principal investigator as part of her Masters of Nursing program.

III. INVITATION AND STUDY PURPOSE

Why are you important in the study?

- Many Indigenous women are living with heart failure.
- We want to learn what it is like for you as an Indigenous woman to live with heart failure, how you manage living with heart failure, and what your experience has been when accessing services related to your heart failure.
- We want to learn about your experience so that as a group we can make recommendations for future programs and services that better meet the needs of Indigenous women living with heart failure.

IV. STUDY PROCEDURES

What will you do in the study?

- You will be asked to share your experience in a one-on-one conversation with the principal investigator that will last about 60-90 minutes. There will be some prompting questions but our conversation is really meant to be an opportunity for you to share what is important for you in terms of living with heart failure.
- This conversation will take place at a location of your choosing that is comfortable for you. If it is comfortable for you, this can be your home or a friend's home. I can also arrange a private room at a library or public space in your community, or a room at TRU if you prefer.
- Our conversation will be audio recorded so I can listen more closely, and to make sure I am true to your words during my analysis of the tape of our conversation
- All information shared during this individual conversation will remain confidential; no identifying information will be included in the results or reports unless you choose to waive this confidentiality and be identified by your name.
- Following our conversation, I will create a shortened version of our conversation, called a condensed story that includes a summary of your experience and what I learnt from you. You will have the chance to review this to make sure I understood what you shared with me in the way you intended. We will discuss this in a follow up phone call. This call should take no more than 30 minutes.
- You will be invited to participate in a talking circle to share your experience with a small group of other Indigenous women with heart failure and make suggestions for programs and services that meet your needs during a talking circle. This circle may include up to 8 women, plus the researcher, and an Elder leading the circle. The talking circle will take 3-4 hours. You will be provided a light meal.
- The talking circle will take place at a local eatery in a private room.
- The talking circle will be audio recorded also, for the same reason as the individual session.
- All information shared during the circle will remain confidential; no identifying information will be included in the results or reports unless you choose to be identified by name.
- A single condensed story of the talking circle will be created by the researcher and given to you for review prior to the final report being written, just as with your individual story.

V. STUDY RESULTS

- The results of this study will be reported in a graduate research report and verbally defended to meet the requirements of my Master's degree.
- The main study findings will be shared with the leadership at Interior health to inform programs and services.
- The findings may also be published in academic journal articles and may be presented at conferences with other health care professionals.

- If you would like to receive a copy of the final report, or be involved in sharing our results please let me know so we can create opportunities for this.

VI. POTENTIAL RISKS OF THE STUDY

Is there any way being in this study could be bad for you?

- Some of the questions may bring up upsetting experiences. Please let me know if you have any concerns or feel upset during our one-on-one conversations or during the talking circle.
- If you do feel upset, I will provide you with a list of individuals who can provide support.
- You do not have to answer any questions if you do not want to. You are free to choose what you share about your experience both in our one-on-one conversation and the talking circle.

VII. POTENTIAL BENEFITS OF THE STUDY

Will being in this study help you in any way?

- There is no direct benefit in taking part in this study. However, in the future, others may benefit from what is learned from you and the recommendations we create together in the circle.

VIII. CONFIDENTIALITY

How will your identity be protected?

- Your confidentiality will be respected. Information that discloses your identity will not be released without your consent unless required by law.
- You choose how you would like to be identified during the written reporting of this research and your wishes will be documented in this consent form, and verified at the end of the study. A made-up name (pseudonym) will be used unless you request to use your own name.
- The audio recordings will be kept in a locked filing cabinet and the files will be stored on a password-protected computer for 5 years following the end of the research project and then destroyed.
- All written documents will be identified by code number – assigned based on enrolment. For example, if you are the first participant, your documents will be coded IWHF 1.
- All written documents will be kept in a locked filing cabinet.

IX. WITHDRAWAL

What happens if you decide to withdraw consent to participate?

- If you choose to withdraw from the study after our one-on-one session, I will ask your permission to continue to use the information we gathered.
- If you decline, I will destroy the audio recording of our session.
- If you withdraw after the talking circle, due to the nature of the talking circle I will be unable to remove only your data from the data collected, so this data will remain part of the study.
- Any data that is part of the reflexive journal will remain part of the study also

X. PAYMENT

Will you be paid for your time?

- To compensate for your time, you will be given an honorarium of $25 for our individual session and $25 for participating in the talking circle.
- You will be provided a gas card for your travel for the talking circle.

XI. CONTACT FOR INFORMATION ABOUT THE STUDY

Who can you contact if you have questions about the study?

- If you have any questions or concerns about what I am asking of you, please contact me at smochz11@mytru.ca or 250-314-2100, ext. 3735.
- You may also contact my supervisor Bonnie Fournier, at bofournier@tru.ca or Star Mahara, at smahara@tru.ca. You may also contact the Dean of Nursing, Donna Murnaghan, at dmurnaghan@tru.ca

XII. CONTACT FOR COMPLAINTS

Who can you contact if you have complaints or concerns about the study?

- If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Chair of the TRU Research Ethics Board at TRU-REB@tru.ca or 250.828.5000

XIII. PARTICIPANT CONSENT AND SIGNATURE PAGE

Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your care at the Heart Function Clinic.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.

____

Participant Name Date

____

Participant Signature

____

Research Team Member’s Signature Date

____

How you want to be identified in research reports. Documented and verified prior to the final research report.

Appendix E

Conversational Method Guiding Questions

Tell me about your experience living with HF? What has it been like living with HF?

Want concerns you most about living with HF?

What is your understanding of HF?

Tell me about your experience with health professionals/health services in terms of your HF?

How have your experiences with hcp affected you?

What might you change to improve your experience? What could hcp do to improve your care?

What do you need to be able to live well with HF?

What services or programs would you like to see offered for Indigenous Peoples living with HF?

Adapted from similar work by Jacklin et al., (2016)

Appendix F

Circle Preparation Letter for Co-creators

Wekt-k/Hello

I am looking forward to seeing you for our learning circle on August 11th at 1pm, at Thompson Rivers University. I have put some information together in this letter which I hope you find helpful as we prepare for our time together.

I have enclosed your "Concept Map" of some of the main themes that came out of our conversation together, and your condensed conversation, with some lingering questions I have. Please take a look and if you are able, bring it with you to the circle. I will also bring a copy too.

The map has 2 purposes;

1. To see if I have identified the same key issues as you would yourself (you will be able to share with me in the circle if I have done this or correct me if I have not).

2. To give you something that may help with sharing your experience in the circle.

What we will do in the learning circle

Colleen Seymour will lead our circle and start us off following Secwepemc protocol for circle ceremony. We will then go around the circle with introductions (your name and where you are from).

The next round in the circle will be for us to share our experience – I will share what I have learned from each of you as I have been working on my initial data analysis. You will have the opportunity to share as much or as little of your experience of living with heart failure as you wish.

The next part of the circle is where I would like to ask you some questions ahead of time to think about, and Colleen will guide us through discussing these. The questions are:

- What kinds of Programs and Services do you need to live well? Think about in your home community as well as from the health authority.
- Who will we share this knowledge with? Some of my initial thoughts are with health care professionals in your communities and nations, as well as with Interior health Leadership.
- How will we share this knowledge? There are many possibilities, such as a digital story or poster, writing in journals, and attending conferences are just a few options.
- How much do you want to be involved in this knowledge sharing strategy?
    - Not at all? Provide feedback on the resources we create only? Being a part of meeting other health care providers?

As a group of women with a shared experience, you get to decide how we move forward in a good way.

Colleen will then close our circle following Secwepemc protocol.

I will bring water and snacks for us, but feel free to bring anything else you may need for you to feel comfortable and safe. I will also bring gas cards and your honorarium. Please do not hesitate to call me if you have any questions: 250 -314-2100 Ext 3735(Monday – Friday 7:30-3:30) Cell 778-694-1204

Kukstem/Thank you,
Zoey Bradshaw, TRU Master of Nursing Student

Appendix G

COVID-19 Consent Form

Remote Consent Form

Research Project Title: Indigenous Women with Heart Failure in The Interior of British Columbia. Implications for Creating Service Delivery Change.

I. STUDY TEAM

Who is conducting the study?

Principal Investigator:

Dr. Bonnie Fournier, Thompson Rivers University, bofournier@tru.ca, 250-318-738.

Graduate Student Investigator:

Zoey Bradshaw, Masters of Nursing Graduate Student, Thompson Rivers University, smochz11@mytru.ca. Phone 250-314-2100, ext. 3735

Thesis Co-Supervisor:

Star Mahara, Thompson Rivers University. smahara@tru.ca, 250-828-5441.

II. SPONSOR

Who is funding this study?

- The principal investigator as part of her Masters of Nursing program.

III. INVITATION AND STUDY PURPOSE

Why are you important in the study?

- Many Indigenous women are living with heart failure.
- We want to learn what it is like for you as an Indigenous woman to live with heart failure, how you manage living with heart failure, and what your experience has been when accessing services related to your heart failure.
- We want to learn about your experience so that as a group we can make recommendations for future programs and services that better meet the needs of Indigenous women living

with heart failure.

IV. STUDY PROCEDURES

What will you do in the study?

- You will be asked to share your experience in a one-on-one conversation with the principal investigator that will last about 60-90 minutes. There will be some prompting questions but our conversation is really meant to be an opportunity for you to share what is important for you in terms of living with heart failure.
- This conversation will take place at a location of your choosing that is comfortable for you. If it is comfortable for you, this can be your home or a friend's home. I can also arrange a private room at a library or public space in your community, or a room at TRU if you prefer. If this conversation cannot take place face to face, it will take place via the telephone.
- Our conversation will be audio recorded so I can listen more closely, and to make sure I am true to your words during my analysis of the tape of our conversation
- All information shared during this individual conversation will remain confidential; no identifying information will be included in the results or reports unless you choose to waive this confidentiality and be identified by your name.
- Following our conversation, I will create a shortened version of our conversation, called a condensed story that includes a summary of your experience and what I learnt from you. You will have the chance to review this to make sure I understood what you shared with me in the way you intended. We will discuss this in a follow up phone call. This call should take no more than 30 minutes.
- You will be invited to participate in a talking circle to share your experience with a small group of other Indigenous women with heart failure and make suggestions for programs and services that meet your needs during a talking circle. This circle may include up to 8 women, plus the researcher, and an Elder leading the circle. The talking circle will take 3-4 hours. You will be provided a light meal.
- The talking circle will take place at a local eatery in a private room.
- The talking circle will be audio recorded also, for the same reason as the individual session.
- All information shared during the circle will remain confidential; no identifying information will be included in the results or reports unless you choose to be identified by name.
- A single condensed story of the talking circle will be created by the researcher and given to you for review prior to the final report being written, just as with your individual story.

V. STUDY RESULTS

- The results of this study will be reported in a graduate research report and verbally defended to meet the requirements of my Master's degree.
- The main study findings will be shared with the leadership at Interior health to inform programs and services.
- The findings may also be published in academic journal articles and may be presented at conferences with other health care professionals.
- If you would like to receive a copy of the final report, or be involved in sharing our results please let me know so we can create opportunities for this.

VI. POTENTIAL RISKS OF THE STUDY

Is there any way being in this study could be bad for you?

- Some of the questions may bring up upsetting experiences. Please let me know if you have any concerns or feel upset during our one-on-one conversations or during the talking circle.
- If you do feel upset, I will provide you with a list of individuals who can provide support.
- You do not have to answer any questions if you do not want to. You are free to choose what you share about your experience both in our one-on-one conversation and the talking circle.

VII. POTENTIAL BENEFITS OF THE STUDY

Will being in this study help you in any way?

- There is no direct benefit in taking part in this study. However, in the future, others may benefit from what is learned from you and the recommendations we create together in the circle.

VIII. CONFIDENTIALITY

How will your identity be protected?

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- The audio recordings will be kept in a locked filing cabinet and the files will be stored on a password-protected computer for 5 years following the end of the research project and

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X. PAYMENT

Will you be paid for your time?

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Taking part in this study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your care at the Heart Function Clinic.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in this study.

If consent is being obtained via telephone at the time of data collection, it is recorded verbally on the tape recorder and the researcher will enter "Remote consent obtained" in the participant signature line below.

____

Participant Name Date

____

Participant Signature

____

Research Team Member's Signature Date

____

How you want to be identified in research reports. Documented and verified prior to the final research report.

Appendix H

Safety Check-In Procedure

- I will contact the designated check in person upon arrival at my location, prior to commencement of the session.
- I will contact the designated check in person at the end of the session when I have left the location of the session and am in my private vehicle. This will be no more than 90 minutes from commencement of the individual session.

- If there has been no contact from myself after 2 hours, the contact person will contact me.
- If they cannot reach me, they will make another attempt within 5 minutes.
- If they cannot reach me after the second attempt they will:
    - Call the participant at their contact number.
    - If they cannot reach me, they may call 911 and request support.

In case of emergency call the following:

Matthew Maidment (Spouse) 250-xxx-xxxx

Appendix I

Participant Condensed Conversations and Concept Maps

Delwiese – Condensed conversation

I'm from the Tse'khene nation and I now live in Kamloops, my name is Delwiese. I am, all my people are, nomadic people, so we travel and live everywhere. I lost my traditional stuff when I was younger because of residential school. My mom used to cook with traditional foods and taught me about traditional medicines until she passed which was about gee maybe 40 years ago. I've never been to a talking circle, but I'd be willing to try, and think that services for Indigenous women that include traditional healing may be helpful. I'm not afraid to question but some native ladies are, so they should have an advocate, that can ask questions. My daughter is an advocate for me. I think its important sharing with my husband and my daughter also.

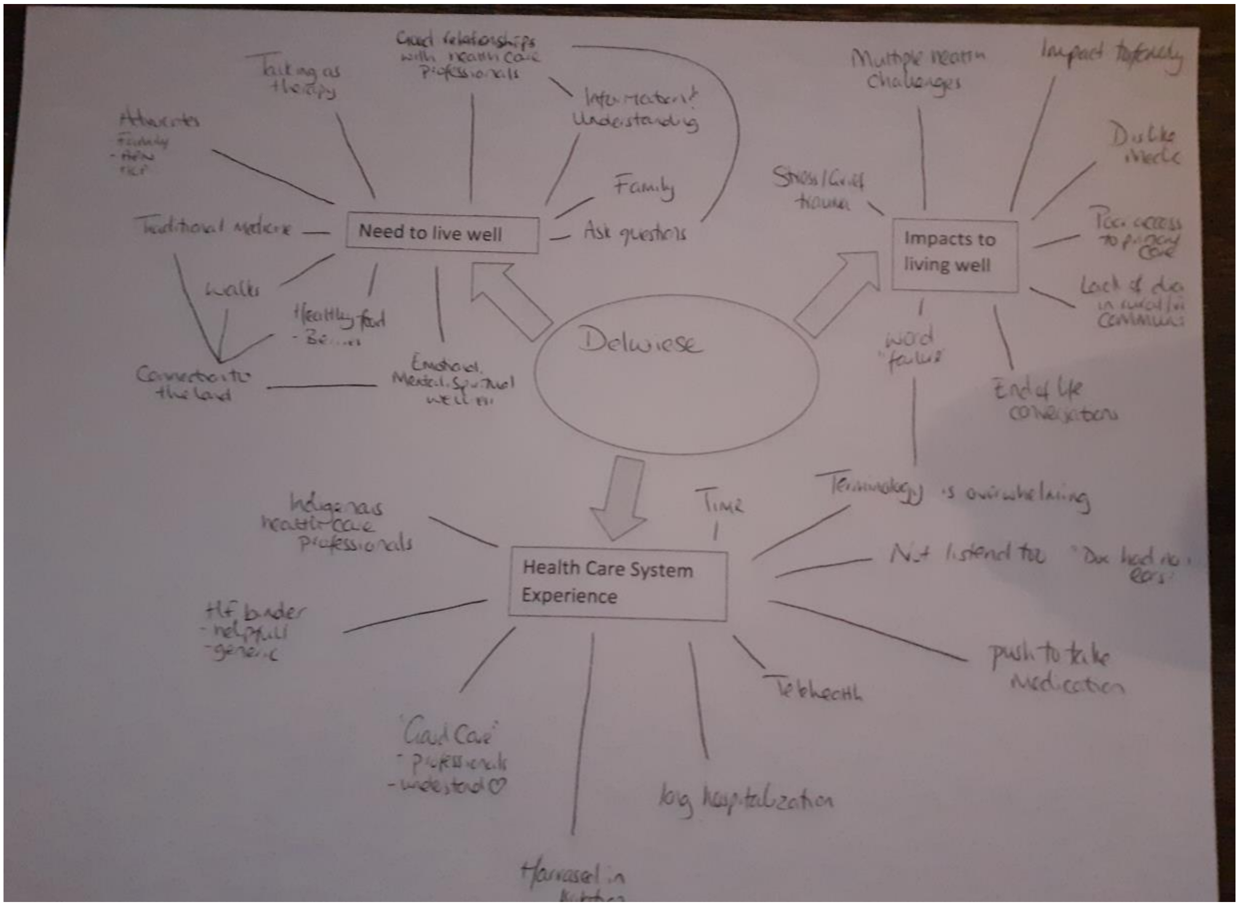
I have lived with a hole in my heart all my life and now they say it's compromised. I went into the hospital with pneumonia and the flu, and my weight dropped to 78lbs and that compromised my heart, only because at the time of the two illnesses. They call this heart failure. Well, I don't like that word. Its stabbing. I don't know how else to say it. Just, from A to B or from 1-10, this is what they always asked, 10 being the worse and 1 the least, heart failure to me would be a 10. When talking to Indigenous women its important to be specific, but use softer terms, and make sure they know its serious, and be out front about everything. I like to have really good care. In my visits to the clinic, I felt comfortable because you guys are professionals, and talking to you is therapy. It didn't bother me that there is no representation of Indigenous culture in the clinic or in the educational material I was given. The educational material that was given in the clinic was good for me. When I was in the hospital the heart doctors that I was seeing were letting me know what was happening. This was important for me. I did have an experience in hospital where I was in isolation. I felt like I was being harassed and was a bother to them. In my last visit to the clinic, I felt like that doctor, he just didn't have no ears, he didn't listen, or see my view. He didn't have enough time. Now that my heart function has gone back to normal, I don't know what the worries all about. I don't know why I would still get pills. I don't really like taking medication. I've slowed down considerably because of my age, like, I'm starting to think is it my age or my heart, I don't know, because of the arthritis maybe.

I had great care in PG with family doctors. They didn't investigate in depth like they do here in Kamloops but they referred me to specialist when I needed. Now I'm in Kamloops I have a family doctor in Logan Lake would you believe. A lot of Indigenous people live far away, so I think the idea of telehealth is quite cool. It's a very good idea. I'm not very good at technology so would need help.

Key learnings for me from our conversation (In no order) (Marked with * for number of times someone else had a similar experience) (With some lingering thoughts/questions I have)

- ❖ Dislike of Western prescription medication, feeling its not needed now heart has recovered.
    - o Is this ab out *stigma? Side effects? Or something else?*
- ❖ Lack of access to primary care
- ❖ Importance of traditional name, a tradition not continued in current generation.
    - o *Why not continued?*

- Lived with a lot of grief
    - Has the l*oss of your children impacted how you feel about end of life?*
- Felt like you had good access to diagnostics and specialist services, GP in PG referred
    - *I wonder if the hole in your heart would have been diagnosed sooner if you lived in a bigger center, and makes me think about access to services in remote and rural communities.*
- Care in the HFC has been mostly good. Got the information you needed, and felt able to ask questions.
- Experience of one doctor not listening, not having time, agenda to push prescription medication
- Talking was therapy
- Impact of stress on wellbeing
- Food for wellness
- Importance of an advocate
    - *How can we increase the advocates available to people?*
- Benefits of Indigenous health care professionals
- Sharing information with family is important/ including them in care
    - *How can we support these wider networks, family and communities?*
- Dislike word "failure"
- Suggestion for how to discuss HF diagnosis; Be up front, specific, make sure they know its serious but try to use softer term than "failure".
- Impact of residential school on traditional knowledge and practices.
- Experience of being harassed, and feeling like a burden to hcp, when put in isolation in hospital
    - *Did this experience impact your trust in accessing services after?*
- Telehealth would be an ok option for people living remotely if the concern was not too serious.
- Walking for wellness –
    - Do you think of a*ctivity as medicine? Connection to the land?*
- Positive attitude
    - Does this positivity relate to h*olistic thoughts of wellness, about linking mental, emotional, spiritual as well as physical wellness?*
- Impact of living with multiple chronic conditions on quality of life and functional abilities, also adds to "pill burden"
    - *How can we support managing this better? Supporting living with the symptoms?*
- HF binder was helpful. OK to not see culture reflected in it
    - *Is it ok because you don't expect to see your culture reflected? But you would like too?*
- Willingness to try talking circle
    - Is this about w*anting to see culture reflected?*



Marilyn - Condensed conversation

I'm originally from Red Stone but moved down here to Kamloops to be closer to the hospital. I live with my husband, 4 kids and 2 grandkids. My Dad was born with heart problems, and I also ended up being born with a hole in my heart. Because of this hole in my heart, they had to perform surgery when I was a baby to fix it. I then got my first pacemaker when I was 13 years old and I remember it feeling weird. It healed ok to begin with but then they said I moved too suddenly and they had to redo the surgery shortly after to fix the wires. Then I had a generator change in 2008, and most recently I had the upgrade to the new device with 3 leads. I now have high anxiety about medical procedures, and I'm tired of surgery, yet I know I have to have more surgeries in the future.

About 3 years ago I collapsed. The doctors said it was because of all the changes to my heart and the surgeries, that my heart is not as good as it should be, so now I have to take pills, and that's new to me. I'm not 100% on board with taking pills, but I am taking them, and I will take care of myself and do what is said in the heart failure binder. I'm sticking with the diet they have in the clinic but it's hard to eat healthy, reading the food labels, and not having food from the can. Eating healthy is expensive and there's a lot of stuff I can't have. For me, it's having the courage to not eat what they're eating (referring to other family members). I'm just going to go with it and stay strong. It's not easy, but I notice my health is a lot better and I lost 9lbs.

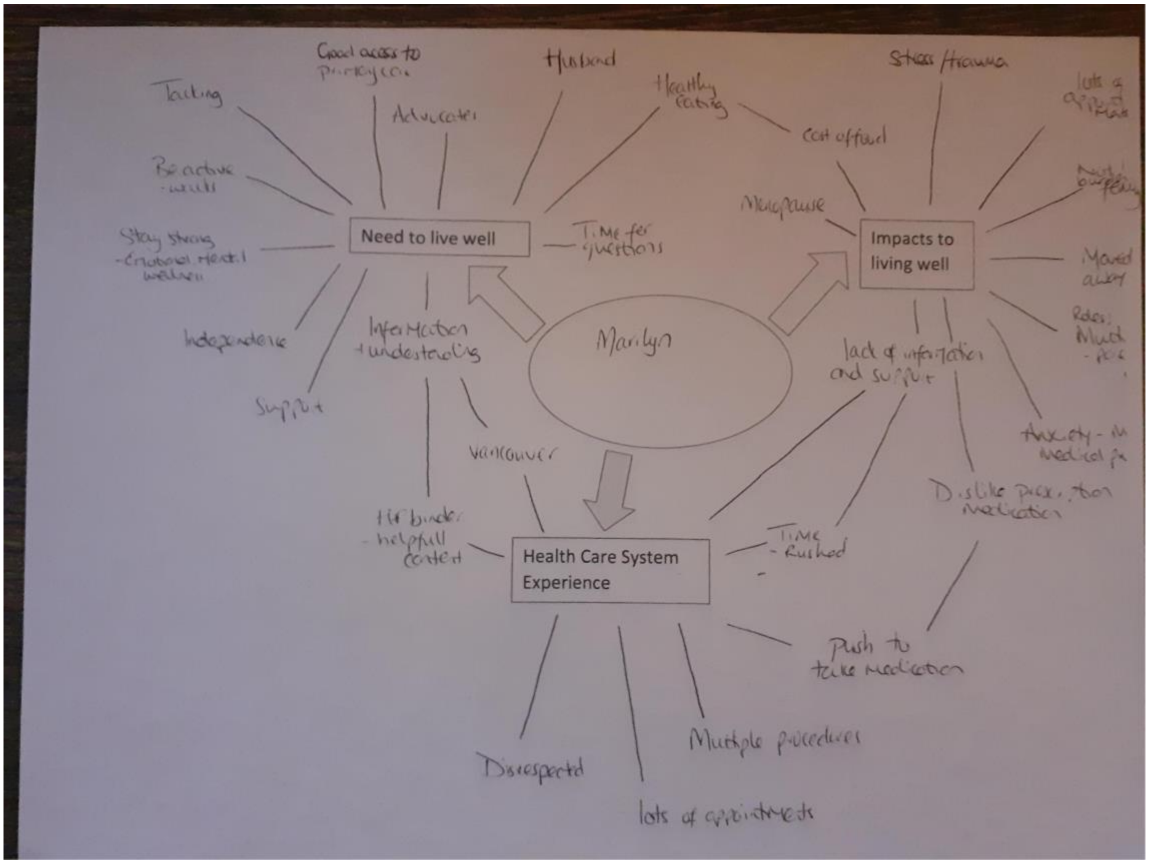
At the clinic they upset me, they say they want my heart to be normal and to do this they want to adjust my medication. But when I was in the clinic, she (nurse/doctor) was going through everything so fast, and at the end of the meeting I thought to myself; holy that was weird. They rushed me so much through the appointment that I didn't pay attention to everything they were saying. They wanted me to weigh everyday but I didn't like that; I would feel self conscious. I felt they were trying to push that on me and I'm uncomfortable with weighing. My bodies changing as well as my heart, it could be early menopause.

My mom, she never had any traditions and she didn't really raise me. Being raised by the Ministry distanced us. So now I deal with everything on my own. I depend on myself, and my husband supports me. Now I think living with these heart troubles is normal and I try not to stress over it, but I wish I had more support. I can't rely on my family and I don't want to burden them, so I want them (doctors/nurses) to sit down and talk with me. I want them to go over the diagnosis and explain to me properly, to give me time to process the information and then talk with me about the medications and changes. While I have support from my husband, some people that I've met when I've been in the hospital don't have the support they need. There's a lot of people out there with heart problems and it's hard to live with. They need to ask around to get help and support.

Key learnings for me from our conversation (In no order) (Marked with * for number of times someone else had a similar experience) (With some lingering thoughts/questions I have).

- Multiple medical procedures throughout life leading to high anxiety around medical procedures
- Dad having similar health challenges
    - *Do you think this normalized medical procedure for you at a young age?*
- Dislikes taking medication
    - *Is this related to side effects? Stigma? Or something else?*
- Good care involves understanding what's happening and having things explained
- Experience at HFC – felt rushed, not enough time to process, medical agenda pushed
- Weighing daily would lead to feeling self conscious
    - Is this about b*ody image? Where does this come from? What prior experience has shaped this?*
- Reliance on self/ taking care of own well being
    - *Why do you feel you have to rely on yourself? Is it linked to being away from family and community so having no choice but to rely on yourself?*
- Focusing on healthy food choices
    - *Do you think of food as medicine? Important for your wellbeing?*
- Challenges with healthy eating
    - *Are you feeling you are missing out on foods your family eating? Is this leading to negative feelings about food?*
- Importance of being active
    - Do you think of a*ctivity as medicine?*
- Bad experience in the hospital, felt disrespected and stereotyped as alcoholic
- Need for advocates for people on their own who are not confident to ask questions
- Impacts of living with heart condition to general life; societal roles as parent and grandparent, and ability to do ADLs/house chores, work
    - *How can this be supported?*

- Local access to primary care
- Had to move away to be closer to hospital
- Impacts of being raised in Ministry home on family relationships and community connection, traditional knowledge
- Interest in trying talking circle
    - Is the interest in trying this related to w*anting to see cultural revival, and connection to traditional ways? Or something else?*
- Having a lot of appointments is overwhelming
- Need to feel more supported – This means having more time to think about information given, being given ahead of time.
    - Do you think feeling supported by clinic staff is *linked to communication and trust of the people?*
- Talking as healing
- Impact of stress on body
- GP in WL, Longstanding relationship so more relational practice, and trust.
- Nurses teaching with check in for understanding or relevance



Della - Condensed conversation.

I was born in Kamloops and have lived here my whole life. When I was born, I was not able to live with my birth mum, so I was in the hospital for a few months and then I was taken in and fostered by a white family. I grew up with them and their three children, and they raised me really well. I went by my birth mom's maiden name, Etienne. When I was about 12, or 13, my birth mum introduced me to my half brother. My brother then introduced me to my half sister, and then years later I met another half brother. We all shared the same mother. Two of my siblings were raised by our grandparents, and one was raised in foster care like me, but he had a very hard life. I found out I had one more half brother but he passed away and I never met him. I always felt I would have liked the chance to know what it was like to live with the native people, but after a while I wanted to keep my distance because I didn't want to get the two mixed up. I didn't want to learn the native ways after all as it just didn't feel right.

I had a check up at the doctors and she said; there's something on your heart. So, she referred me to Cardiology and I had some tests done. Then they called me and said that I needed to come into the hospital right away. I had been feeling okay when this first started but when they called me that was when I started noticing I was having a hard time getting up the stairs. So, I go to the hospital, and the doctors says to me "I hear you have heart failure". But I really didn't know what that was all about. So, they admitted me to the hospital and I ended up having a pacemaker put in. Right after that, the doctor comes to see me and says, now we have to send you to Kelowna for a stent. The whole time I'm in the hospital I really didn't know what was going on, they didn't explain or I didn't understand. They would ask me if I had questions but I couldn't think of what to ask. So, 3 or 4 days later they come in and take me to Kelowna, and I'm scared stiff as Albert can not come with me, and Id just had the procedure to have the pacemaker put in, and it turned out I didn't need a stent after all.

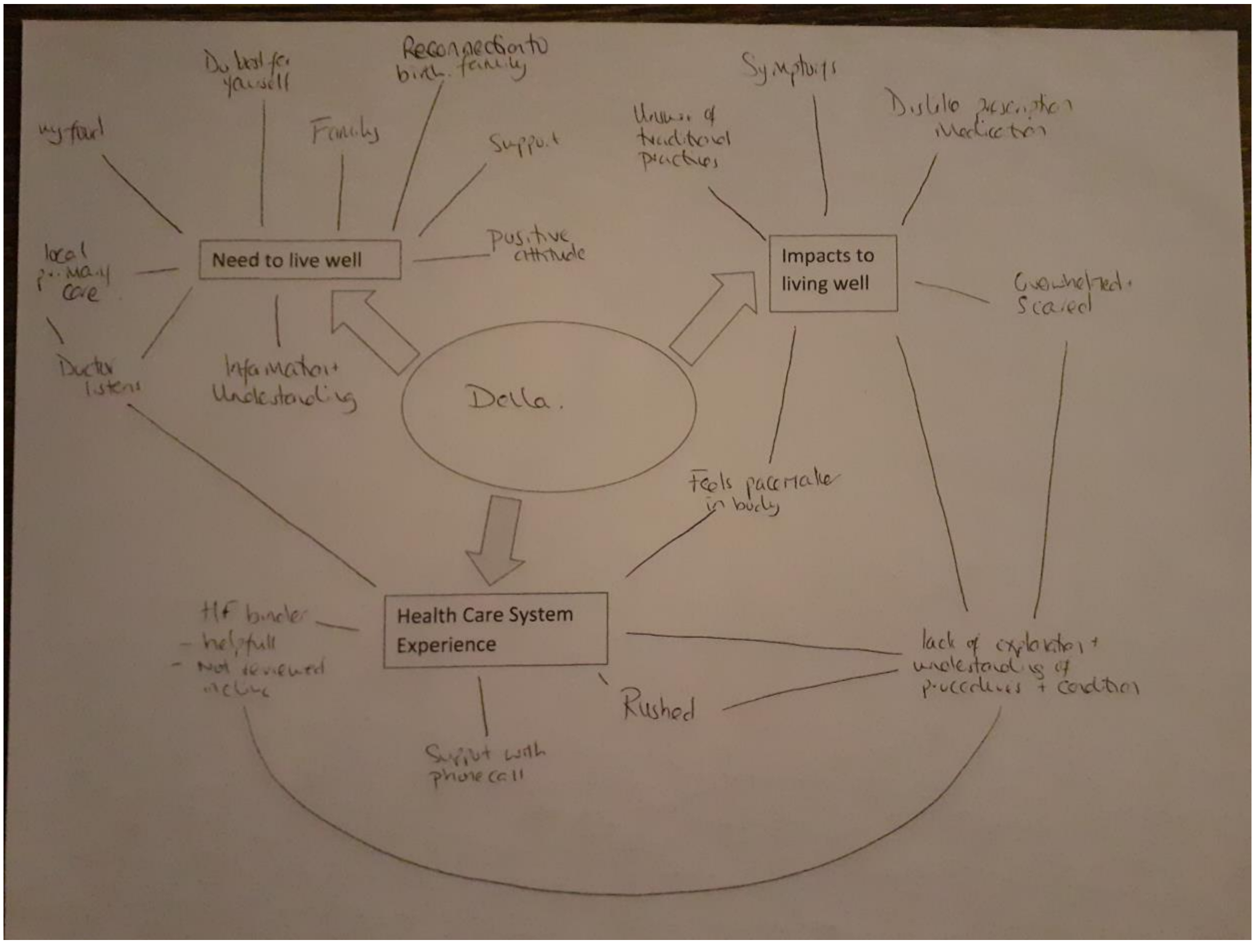
Laying in bed after the pacemaker was put in, I didn't realize there was something on my heart, or that I needed the pacemaker because I was running out of energy. They didn't explain where the pacemaker was or what it was for. At first, I could feel the pacemaker when I laid down in bed. It didn't hurt but it felt heavy, it felt funny to have something there. Sometimes I feel like I want to just take it and take it out. Now it's been in for a while, I feel it now and again and its something I had to get used to, which I have now that it's settled down into position.

A month or so after leaving hospital I went to the clinic and they gave me the heart failure binder. They explained a bit while I was there but I didn't understand why I needed the binder, so I didn't really look at and I carried on eating whatever I felt like eating. When I did look through the binder at home, I couldn't see why I couldn't have the stuff listed in the binder. I had been eating the foods on the list and it didn't make me feel unwell. I don't mind weighing everyday but I didn't realise I needed to weigh myself. I don't like taking medication but I know the doctors say they have to be taken so I don't mind taking them. My family doctor is very helpful and listens. Its great to have the HFC phone numbers to call if I have problems but I wish they had explained the binder better. If they had told me this was why I was having a hard time getting up the stairs, because that's what I noticed, it would have been better. For me, living well with heart failure means making the best of it, and doing the best I can.

***Key learnings for me from the conversation** (In no order) (Marked with * for number of times someone else had a similar experience) (With some lingering thoughts/questions I have)

- Experience of being raised in a foster family
- Experience of reconnecting with birth relatives
- Importance of name – using mother's maiden name
- Concerns about mixing white and Indigenous ways

- Many times, medical interventions/procedures/conditions not explained in a way that is understood
- Feeling rushed
- Feeling scared when you don't really understand what's happening
- Connection between symptoms and lifestyle recommendations not explained in a way that makes sense
- Symptoms biggest concern
- HFC supportive knowing can call them if needed
- Don't like taking pills
- Important to do the best you can for yourself



SLC- Condensed conversation

I was born in Lytton hospital and raised in Boston Bar. I'm from Anderson Creek band, that's Boston Bar first nation (Nlaka'pamux). I was raised by my Mum and Dad, and then they separated and I ended up having step fathers. I am the oldest with two sisters and a brother, but there's only my brother and I left now. When I was 12 years old, I started work and I've worked most of my life until I was 70 years old. I went to college in Kamloops in 1985, where I took horticulture and looked after the grounds at TRU. Other than those few years in Kamloops I have lived in Lytton. I enjoyed working, but if you just told me verbally what you wanted me to do, I wouldn't be able to concentrate long enough to get it all. But if you showed me how to do a job, I could find an easier way or a quicker way to do it. I have 1 son and 2 grandchildren, and I love dogs. I keep asking my son when I am going to be a great grandma as I'm not going to live forever.

I tell people that when I was born, I was greedy; I took everything that was handed out, I took everybody's sickness, like with my lung condition, my heart condition, arthritis, and diabetes. In 2000 I was spitting up blood all night this one night, and after talking to my Mum I went to the doctor and I ended up in the hospital for 9 weeks as my lung had collapsed and they did not know why. This was when they first told me there was an issue with the valve in my heart. So, they have been watching the valve, and finally this last year I started to notice that I had more trouble trying to walk up steps, that I was getting out of breath. Now the doctors tell me I may need to have an angiogram and surgery on my heart.

When I have been to the hospital or medical appointments everything's been really good, I've never really had any trouble. My first time at the Heart Function Clinic I saw the nurse and then we talked for a little while and she gave me this book, and said to bring it with me every time I come in, yet we didn't even look at the book when I brought it in the second time. I read some of the book but I never really finished it, and no one went over the book with me.

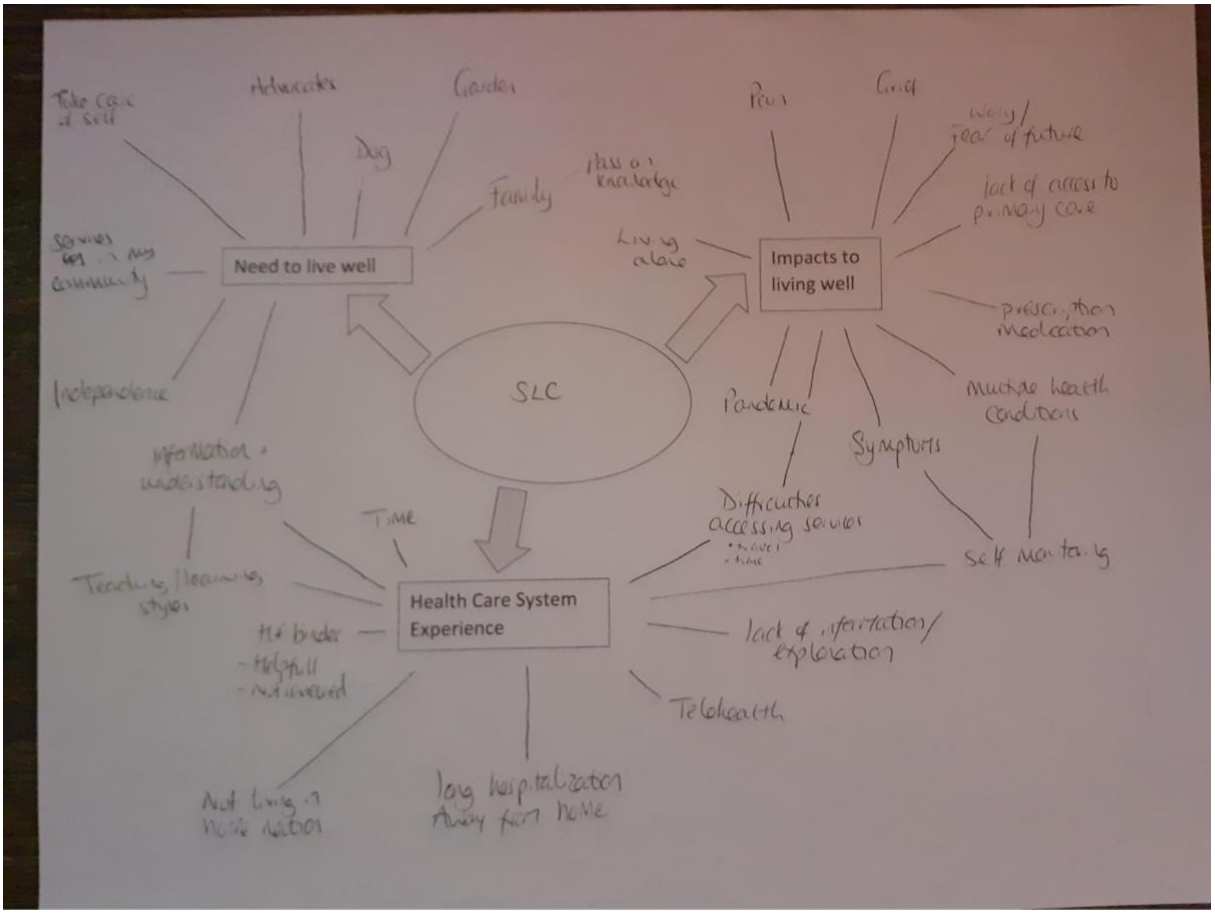
Thinking about my health, its my arthritis that's giving me all my problems, more than my heart. Some days I have a lot of pain and I can't do as much as I want to do. I live by myself and it is hard to get help. The doctors and nurses suggest I wear those support socks, but there is no way I can put them on. They also want me to check my blood sugar, but I don't check every morning as its hard to use the machine. Its even harder to get somebody to come and cut your lawn for you. I take eight pills in the morning. I don't have troubles with the heart pills but the arthritis pills; I'm not supposed to go out in the sun and people look at you funny all covered up on a hot day.

It takes 2 hours to get to Kamloops, which is a long way to go in to an appointment for 15 minutes. So, anytime I have a doctor's appointment I usually try to line them all up so I have 2 or 3 the same day. I also wonder why they often book a 9-o-clock appointment when they know I live out of town. Telehealth would be ok to reduce travel to Kamloops. Because I'm from Boston Bar band and not Lytton band, I can not access services with the Lytton band. There is also a different organisation, Tribal, for helping with transport to medical appointments. Its hard to access services. I would be interested in traditional medicine, I know the Elders can help if you have arthritis, they go in with the stinging needle. I would try services for my heart that included traditional healing and medicine. When I go to the hospital and there is native art, I look at that and I enjoy seeing some of that.

Key learnings for me from our conversation (In no order) (Marked with * for number of times someone else had a similar experience) (With some lingering thoughts/questions I have)

- Importance of family and passing on knowledge
- Value of working hard
    - *Did you work so many years because you had to for the financial support or did you enjoy working and that is why you continued?*

- Lack of explanations from health care professionals
- Taking care of self/self reliance
    - *Have you always felt like this, or is this a new feeling know you live alone? Where does this come from?*
- Information is important to feel supported and to manage health conditions
- Need to link symptoms to condition, managing daily symptoms to living well with a condition
    - *Would understanding how your conditions leads to symptoms make it easier to manage? Would linking symptoms to daily activities make self monitoring more relevant?*
- No assessment of literacy or learning style when providing education
- Difficulty accessing services provided in communities when home nation is different
- Difficulty accessing primary care and specialty services
    - *Making multiple appointments in Kamloops on the same day to overcome the distance challenges must be very tiring? Do you feel by later in the day you are too tired to get the most out of your appointments?*
- Telehealth an option.
    - *Any instances when you feel telehealth would not be ok?*
- Biggest challenge is not HF but the impacts of other health challenges
    - *How can we manage this? A service for those with multiple conditions? Extra services such as occupational therapy, social work, physiotherapy?*
- Medication and side effects impact daily life
    - *Are the effects of the medication worse than the underlying health issues they are treating?*
- Interest in services that combine traditional healing with western health care services



Dell - Condensed conversation

I am Secwepemc first nation from the Adams Lake Indian band. My mom is Sarah Deneault (August) from Neskonlith, and my Dad is Aleck Deneault from Skeetchestn. I have 12 brothers and sisters, 2 sons, 9 grandchildren, and 2 great grandchildren. I've been working all my life, mainly for the Neskonlith Indian band. I am very active in powwow and ceremonies, in the community garden, and I do the Sun Run and Boogie the Bridge. Since my heart, I had to slow down a bit, but I am still very active in the community garden. Interested members come and plant whatever they wish, and look after what they plant. Some would rather get it from the store because its right there, they would rather have things easy, but the garden is a great way to connect with the community. We would have a big dinner or pot luck with veggies from the garden, and the men go out hunting and get wild game and salmon.

Now I am semi-retired, and I'm really trying to plan what to do as I'm so used to working and my mind won't slow down. So, I am thinking about learning the language, and also learning more about medicine, as we need to pass this knowledge down the line. The community is hungry for that knowledge and there is a minimum amount of people that know. So, I take my grandkids out to the mountains gathering medicines and berries. We gather a lot of different medicines that would help with whatever ailment. There are specific medicines for each ailment, and I'm learning from a couple of ladies in the community. Many prescription medicines make me sick, so, I'm really leaning more towards traditional medicines than taking medications that are going to make me sicker. I have knowledge from my mom, and my grandmother Lena Marshall (Dennis).

I first got diagnosed with heart challenges in 2002 in San Diego, California. I had a heart attack and they put a stent in to open up the blockage. I came home so my family could help me but there was no follow up. I didn't see a cardiologist and there were no doctors in Chase, so I was left with nothing. Then 2 years ago I didn't feel very good and they found out that that stent was re-plugged. That was when I got connected to the heart clinic in RIH. The clinic was so supportive, and I was happy that we have a whole section just for the heart. I think there should be follow up in the Adams Lake community too though. We are left in the dark. The health center should have a support group for those with heart challenges. Somebody needs to take the lead, to call us for a meeting, and we can support each other. We can sit down, have a coffee and just shoot the breeze, and share our experiences. Maybe do meditation, yoga, or go for a walk. A cardiologist or other health professionals could come to a meeting and we can ask questions. I feel alone sometimes and it's hard. It's scary for families going through that too. We need support from the band to help families and the whole community understand what the individual is going through, what the outcome will be, and how they can help.

I found the heart failure binder to be very helpful and I did learn a lot, but it would be more helpful if we had someone else to talk too about the binder, to sound off too. It would be nice to see my culture reflected in there with reference to traditional foods, and maybe a few recipes. We also need to employ more Indigenous healthcare providers who are able to relate and understand where you're coming from. The patient navigators do an awesome job at the hospital and it would be great if they were there for out-patients too. To help you and guide you after the fact, because when you are sick and you don't know what's going on, you're disorientated, especially when you are really sick and if you're an elder and you go by yourself.

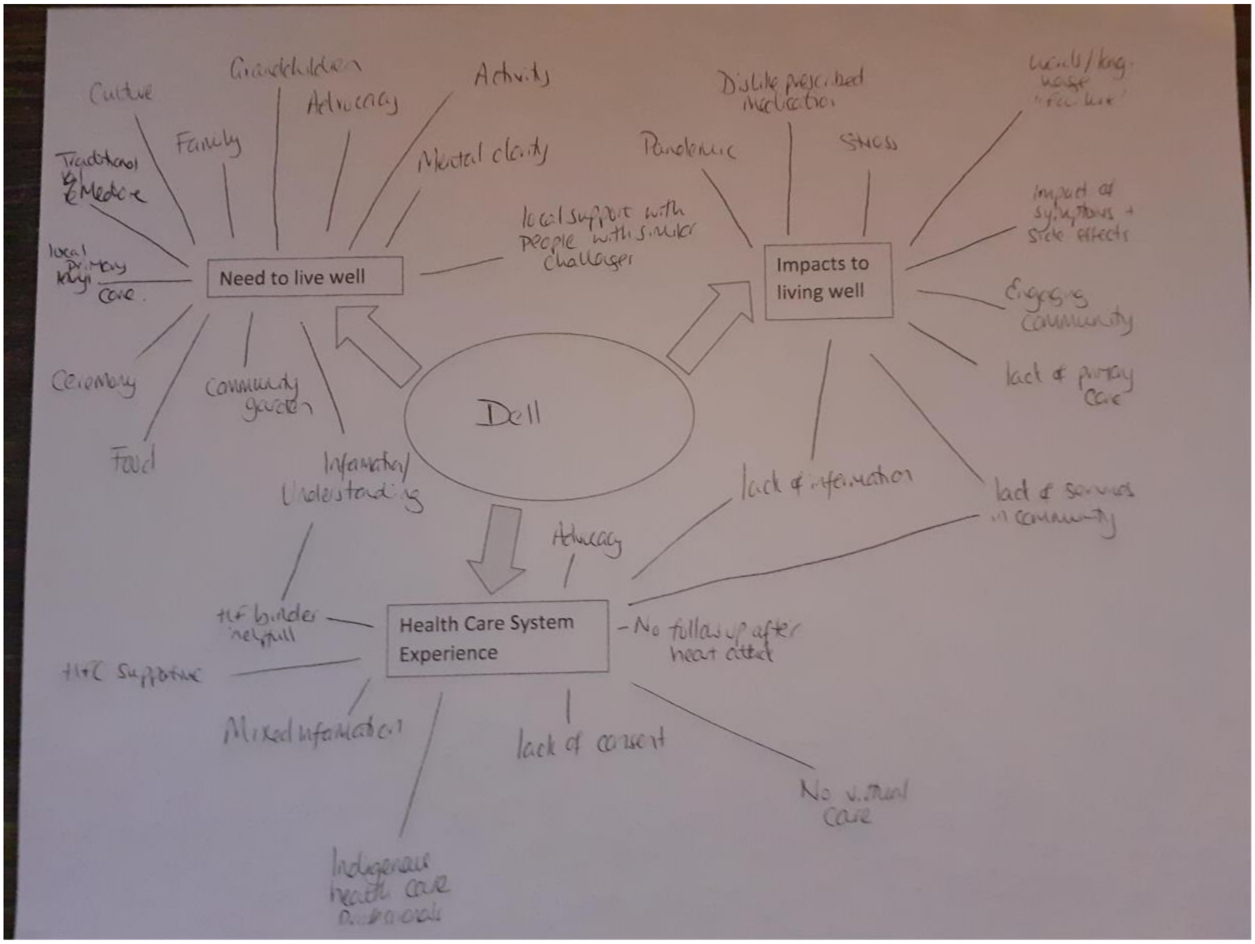
Feeling supported and being given information is important to feel well. The doctors in San Diego explained everything. I would feel better if I had more understanding of the medication. They don't tell me why I'm on it, the side effects, or explain what may happen. It feels like they are guessing, and I don't want them to guess with what to prescribe for me. I don't put things in my body that are not going to help me. Keeping active is important for wellness, and healthy food is also important for me to feel well. We grew up on salmon, wild game, we had a farm with chicken, and turkeys, and we had cows. We didn't go to big stores; we ate what we grew. We had big gardens, we learnt how to dry and salt the meat and salmon, and preserve. I also need to feel spiritually, and mentally well, with meditation, prayers, and ceremony. I think it's important to have clarity in the mind, and an understanding of what is heart failure. Except I don't like the use of the word failure because to me that sounds like a death sentence. You can say heart challenge, or heart problems, I can cope with that. Words can mean so much.

I had a bad experience when I got really sick with Quincey. The doctors are telling me "you can't diagnose yourself" and they wouldn't listen. I thought I was going to die, there was no one there to talk for me, to help me, and they wouldn't listen. I couldn't swallow, or talk. I was totally helpless. They shipped me to Kelowna at 2 in the morning, and the doctor, he opened my mouth and he stuck the scissors in my throat and he cut something. Blood and pus came out and I was choking. I had to write a note to say put me under. After he took off, and he didn't come to see me. He was sly and cruel. Next day, they told me they took my tonsils out without me knowing. They said I wouldn't get it again and then 3 years later I did.

I believe that fi we all work together and understand that living with heart challenges is okay, and how we can pass this knowledge and awareness to others will be so helpful. We can work with our health department council to see what support they can provide for us.

Key learnings for me from our conversation (In no order) (Marked with * for number of times someone else had a similar experience) (With some lingering thoughts/questions I have)

- Importance of family and reviving traditions
- Difficulties engaging communities
- Impacts of pandemic
- Lack of services in home nations/communities
    - *What services should we advocate for? How can we build services? Who should lead this work?*
- Importance of seeing culture reflected
- Dislike of prescribed medication
    - *Is this about side effects? Stigma of drugs? Or something else?*
- Benefits of traditional medicine
- Feeling experimented on
- Lack of information/explanation
- No interest in virtual care. Values relational and in-person care
- Need for Indigenous health care professionals and expanding APN role
- Support for families and communities from local communities
- Lack of informed consent
- Dislike word failure
- Mixed messages from health care professionals
- Wellness needs a holistic approach – food, activity, ceremony. Spiritual, mental, emotional, and physical wellness.
- Stress as cause of health challenges
- Connection to the land with community garden.



Margaret - Condensed conversation

I grew up in Sicamous with my parents and moved to the reserve in Squilax in 1980. I had 5 children but the 2 oldest passed away through violence, and so I have 2 boys and a girl left, and their children. I got cervical cancer in 2010 which was operated on, and then in 2014, I was diagnosed with stomach cancer and sent to Vancouver for stem cell treatment and chemo. In 2015, I got really sick and I couldn't breathe. My lungs weren't working properly and they were getting worse day by day. The specialist told me I should get my will in order because they expected me to die, but then the specialist in Vancouver said my lung problem was possibly from the chemo drug. Once he told them what to do, I started getting better. When I was released from hospital, I was on a lot of medication, I had lost a lot of weight and was very weak, and I was still struggling to breathe. I was scared, but I slowly got a little bit better. Then I was diagnosed with my heart not working properly.

Sometimes I don't feel as sick as other times. I panic when I can't breathe properly but I'm trying to cope. It's very scary. The doctors really don't say much to me as they think I can't handle it. What I really need is a home maker to help with household chores I can't do. It's frustrating to not be able to do things. Now with the virus it's even more difficult to get somebody to come and help. Before the virus, someone came in for 1 hour a week to help me. I think this is too little of a time, and they should be doing more to help elders. They have a nurse in the office, and bathing if you go over there. They do shopping, but it's when they want too. They pick up medication but it's always at the wrong time. I run out and they're not ready to go so I just do it myself. There are things they could be doing better. Most of the time when I've been in the hospital it's not been too bad, but it really depends on who the nurse is. The hardest is when they isolated me and I felt so alone. I have not had good experiences with the APNs as they think your family should help you instead of them. It's surprising to me, but my family aren't there to help much. It would be great if there were groups I could attend, to talk and hear other people's stories. Families don't really understand what you're trying to them, and don't want to talk about how sick you are. When I was really sick in ICU, my oldest son came in there, and he didn't think it was serious. He brought his medicine in and I didn't like that. So, having a family discussion about my health is something that might help, because if they understood what I was going through I could talk to them more.

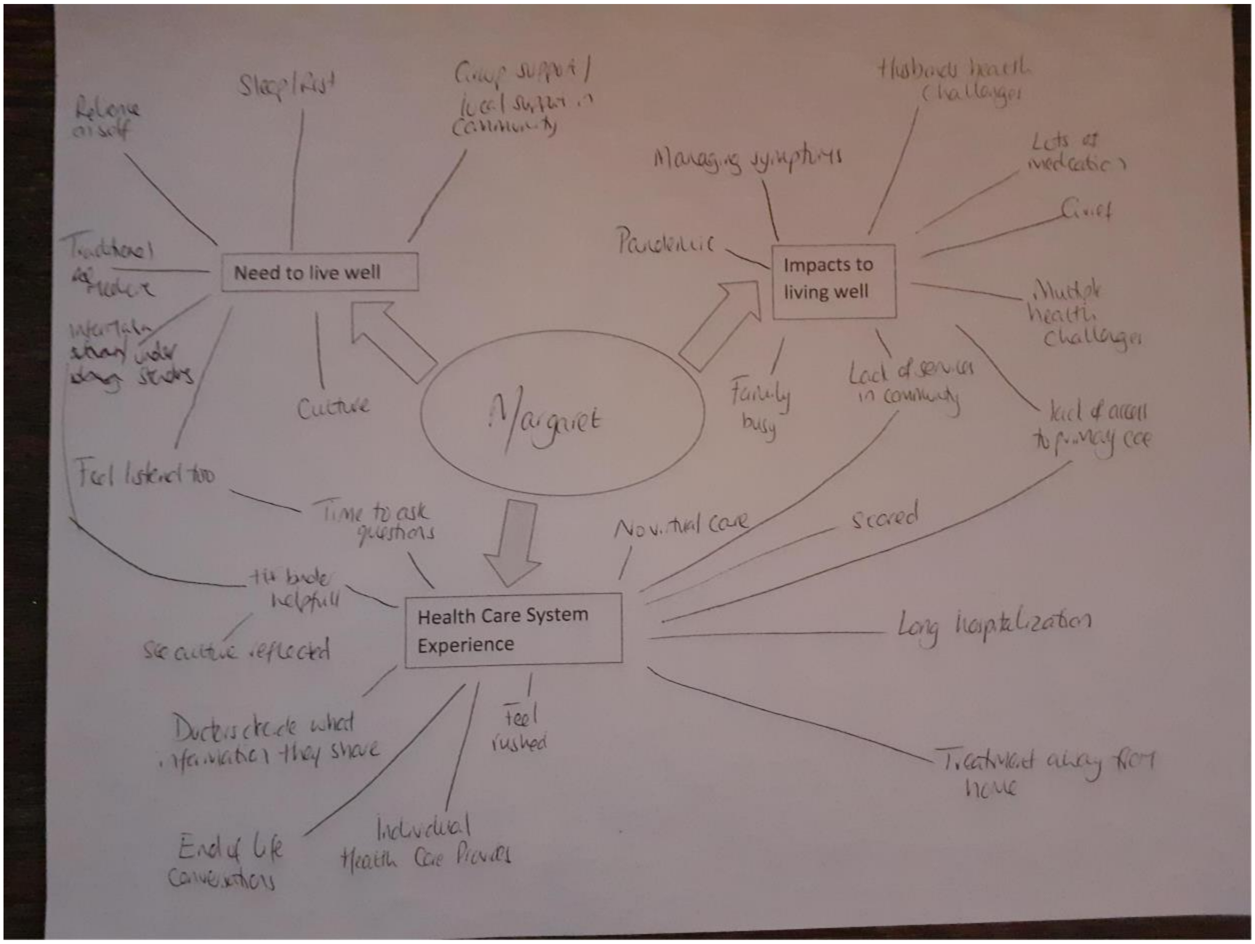
My first visit to the clinic I met the lady doctor and I liked her. She talked and asked me questions, she asked if I had questions and gave me time. On another visit, I saw the man specialist and he was very fast. He wanted to just get the visit done. I liked the heart failure book as it had good information in it. It would be nice if it also included traditional medicine, and maybe foods. But lots of traditional foods are greasy because of how it's cooked. It would be a good idea if there were simple recipes, because people living with a heart condition don't want to take a lot of time to cook. I have been doing medical appointment on the phone because of the virus, but I would rather see them in person, even if it means travelling. I would feel more supported if I had more appointments too, as I only go every 6 months.

When I was diagnosed, I was given medication that's helped a lot. I have to take it to survive and that's what made me better. I use traditional medicine too; burdock root and mullein tea. I learnt from my grandmother and my own research over the years. I'm trying to pass on this knowledge to my daughter. I don't do any ceremonies because the steam bothers my lungs, and some of the ceremonies you have to stay up all night and I don't sleep well. Getting enough rest is important for me to feel well.

Key learnings for me from our conversation (In no order) (Marked with * for number of times someone else had a similar experience) (With some lingering thoughts/questions I have)

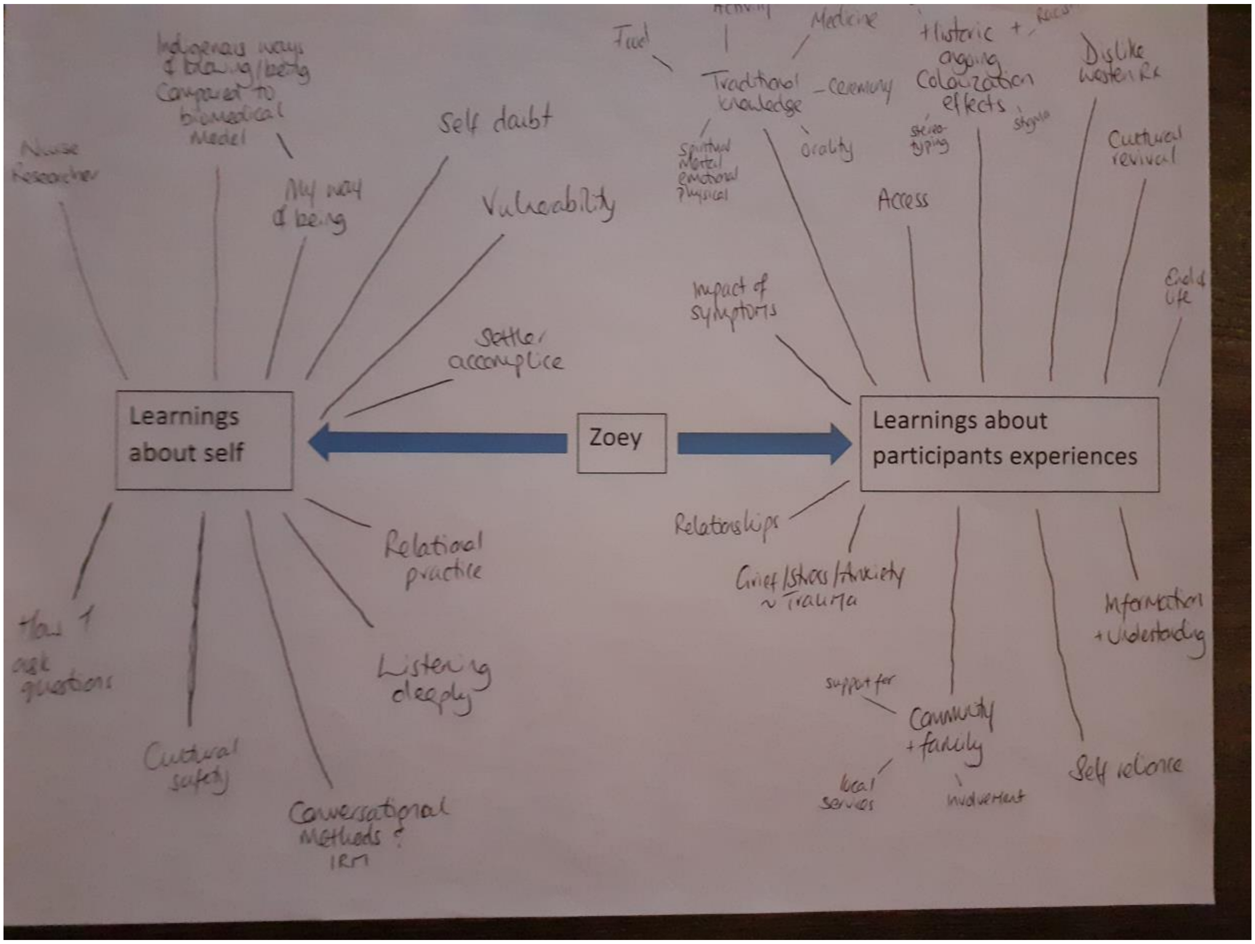
- Impact of symptoms on daily life
- Impact of multiple health challenges
- Importance of rest for wellbeing
- Living with grief
- End of life concerns
    - *How should we be having these conversations? What wording can we use to make this better?*
- Dislike's telehealth, preferring in person, relational health care
- Lack of services in local communities
    - *Who should lead increasing local services and what services should these be?*
- Lack of services to support families and communities
    - *What kind of services would be helpful?*
- Benefits of traditional medicine alongside Western medicine

- Need for sharing with people with similar experiences
    - *Who should lead this work? In your community or at the clinic?*
- HF binder helpful – Add simple recipes, easy/less time to cook
- Lack of access to primary care
- Information and time are important for good care
- Feeling rushed and not given information leads to poor experience
- Doctor's control what information patients are given
- Differing levels of participation in cultural practices and feelings when own beliefs differ to family
    - *Did you participate in traditional practices more before you became unwell? How does it make you feel when your son has such strong beliefs about traditional medicine and you don't feel the same/ cannot join in as much now because of your health?*
- Importance of the individual professional for a good experience
- Impact of pandemic on someone living with chronic condition



Appendix J

Researcher's Personal Concept Map



Appendix K

Circle Condensed Conversation

August 11th 2020 – Learning Circle: Condensed conversation

- Condensed version of what we each shared with each other about our experience. – This will be added to the individual condensed conversation and concept maps.
- Condensed version of general ideas/suggestions about programs/services/changes we would like to see, formed as a group. - This will be used for knowledge translation strategies.

Zoey

I moved from England in 2006 and have been lucky to call Kamloops my home since then. I am thankful for the privileged of living, working, and playing in the ancestral, traditional, and unceded territory of the Secwepemc people in Secwepemculew. I have been learning about the experiences of women who live with heart failure; what it's like to live with these heart challenges, the difficulties accessing services, struggles with taking medications every day, the impact of symptoms on daily life, feeling rushed when at appointments with health care professionals, not getting the information needed or understanding what is happening. I also learnt about the significant amount of stress, grief, and trauma, that many of you live with, and how that impacts health and wellness. I learnt a lot about what it's like to live with heart challenges from the stories I heard, but I also learnt a lot about myself. I learnt about being vulnerable and doubting myself, about my way of being and having control over most situations but not this one. I learnt about proper process and protocol, about being honest, having good intentions, and listening more deeply. I learnt about cultural safety, and how ineffective cultural safety training is, compared to this experience. I believe this experience has given me the ability to provide more culturally safe care, as well as recommendations for change for health care leaders.

S.L.C

I used to go by S. Lorraine Campbell as I didn't like the way my first name was spelt, and now I go by Lorraine. I was born in Lytton. In 1964, I got a job there, and that's where I more or less stayed. I still live there today. In 2000, I was spitting up blood one night, and the next day my Mom took me down to Hope. They put me in isolation, because they figured I had TB, but my lung had collapsed and they never found out what was wrong with me. I was in the hospital for 9 weeks. One of the hardest things I ever had to do was walk up 5 steps so I could be discharged. Since then, they have been watching my heart, and finally this year I've slowed down. I had trouble going up just 10 steps, but before I was doing Tai Chi, and yoga, and walking. It's harder for me to breath now. I'm also anemic, having a hard time with gout, with infections deep into the bone that won't heal, with diabetes, with arthritis. I was really hit this last while with a little bit with everything. I always say to people; when I was born, I was greedy. I took everything from all my family because they knew I could deal with it (referring to the multiple health challenges she lives with). It's hard for me to get anybody to cut my grass, to help around the house. Its hard to get to Kamloops for appointments, so if I go, I try to make it to 2 or 3 on the same day.

Dell

I'm Dalla, Dell. My Mom is Sarah August Denault, and her Mom is Lena Moses Marshall Dennis. My Dad is Aleck from Skeetchestn. I lived in Skeetchestn until I was 8 when we moved to Chase. My Mom and

Dad had 8 kids and when they separated, my mom raised all of us. Then she met Wilfred John, and they had 5 kids. So, all in all we had 13 in the family. We were raised with big gardens, waking up at 4 in the morning to water. Having to pick all the garden, drying, canning, and then it was time for the salmon. We survived hard times but we didn't know about hard times, as we thought it was just regular stuff. Nowadays it's so different. I got the community garden going in Chase, and when I went to check on it, it's all dried. It's devastating, everything's gone. I have 2 boys, 9 grandkids, 2 great grandkids, I'm so blessed.

I was in San Diego California one morning taking a shower when felt a heaviness in my chest and I couldn't breathe. I called 911, and they came and took me to hospital. They wheeled me into this big place, with nobody talking to me, nobody saying what's going to happen, and I was freaking out. They said I could watch on this camera, what they were doing to me. And I saw this little snake coming up to my heart, and then it opened it up. Literally I could see it. After the procedure, they wheeled me back out, then they give me a paper and said its all here what you have to do after. They didn't sit down with me, explain what's going on. I was freaked out, way down in San Diego, and my husband works every day. So, the band office got me a plane ticket and I came back home. It's really bad when they don't tell you what's going on, and you're left in the dark. The second time I experienced heart challenges I had a pain, and they took me to do the same heart procedure again. It was the same stent that got plugged, and they opened it up again. I'm active; I participate in the Sun Run, and Boogie the Bridge. I do yoga, meditation, gardening, hunting, and fishing. I know I have to be active, to keep moving. That's the secret of life; To keep your heart pumping, to get all that beautiful blood all over your body, way down to your feet and all the way back up to your brains. The doctors, they figure they're right all the time, and I have no right to talk and tell them what I think. It's the same with medication. But we know our bodies, and our bodies know what we need. So, I'm really looking after myself now, I'm learning to speak up for myself and I'm so proud. Before I listened like an obedient child. Not anymore.

Margaret

I am Margaret August, Chaleen and I was born in Enderby. I had 13 siblings but a lot of them died. The older ones, from alcohol, and the little ones from not enough food or not being taken care of. My Mom left Squilax when she got married and lived in Sicamous, so that's where my home town is. I went to school there until grade 7. There was too much alcohol around, too much fighting. So, me and my sister ran away. Welfare came and took my youngest brother and sister, so we went and hid. The people whose houses we lived at, they hid us, because they knew what the Welfare people did to the native people. I had 5 kids. Tony, my oldest son, his dad died the same day I found out I was pregnant with him. And then I had Tracey. I had 3 other kids after that and they are the only ones left now. The 2 oldest passed away, from drugs and alcohol. There's a lot of sadness that goes with that. Sadness before they passed, because they reached out for help but there was nobody to help them. I always said I wasn't stressed out, but I guess I was deep down and just didn't admit it or kept trying to be positive.

In 2010 I got cancer for the first time, and this went into remission. Then the second cancer was in 2014. At that time, I thought positive and prayed a lot. My heart was good before all of this happened; I had a good heart. I still don't fully understand that whole cancer treatment. I was always a walker, I walked all over the place. This one day I was half way up the stairs and I stopped. I couldn't breathe. I was shocked. I didn't understand what was going on. My heart was racing, I couldn't breathe. I was in the hospital getting worse and worse, and I could barely breathe, I couldn't walk or get out of bed. I was in ICU and the doctors said they couldn't figure out what's the matter with me, they didn't know how to treat me. They told me I was dying. I kept telling them to speak to the cancer doctor but they didn't listen. Finally, my doctor came in and did phone the specialist in Vancouver and they figured it out. I slowly started to get better. When I was sick, the doctors really didn't explain very well what was going on. I was too sick to understand. My daughter tries to be there to listen.

Then they discovered I had a heart problem, probably from all the chemo. My heart wasn't pumping, I was down to 25%. It took about a year for all those pills they gave me for that to start to work, and now It's back up to 50%, so that's a good sign. It only stays like that because of the pills I'm on. So, I used to be a very active person, we always had a huge garden, we used to have chickens and turkeys, and I used to do a lot of canning, but now I can't go outside very much. The heat and the cold bothers me, so, in the house is the best temperature. Coming up the stairs I have to rest half way, so it's not a very good way to live. But I try to stay positive because I know negative thinking keeps you sick. I'm just kind of surviving. When your sick, your kids don't really believe your sick. Mine don't believe I'm going to die; they think I'm going to live forever. So, it's hard to talk to them, and they get angry with me. Some people dread the thought that they are going to die, but I've been sick for so long, with different things happening, that its life happening. If you can't get fixed, you can't. I just have my prayers, and my congregation, and my meditation, my eagle feather, my rocks, and I go to the river if I can.

Group recommendations

Some doctors think that you don't know, or need to know. Native people have the knack of not asking too many questions because we've been told to be quite so much. So, we don't ask, we don't say, and we don't understand. So, we need to share our experience with other people that get what we had, so they can understand it. Understand these things that you have to keep battling in life. If there's more information out there, of what we've been through, how it was dealt with, and how we felt, it would help more people, because there's not enough information for people.

We have to share these experiences in a pamphlet, or book, or something for others to read. Put it in a form where its easy to understand; not in all those big words either. It needs to be in a format that women who get these kinds of disease can understand it.

- Information for Individuals living with heart challenges
- Advocacy
- Sharing stories

Sometimes you have good doctors and good people and that makes a difference. Some people won't do anything for you. All they talk about in the hospital appointments is medication, and the medical parts, so people need information about what it is like to go though these experiences, and how we ourselves came to cope with it. It would help a lot of people.

- Relationships with Health Care Providers
- Cultural Safety/competency
- Life beyond heart failure diagnosis

I always wanted to go to a support group because there must be more people out there that have what I have; somebody that's going through the same thing, so we can talk to each other. Our own families don't want to hear us talking about it all the time. We need continued support after the initial diagnosis, and to support each other. We need a group, to share experiences, life, and to encourage each other. We have to get out there and do it. No excuses.

- Support group in communities
- Supporting families/communities
- Sharing stories with each other
- Indigenous led services

I believe if we all work together to understand what it is like, living with heart challenges, and how we can pass this knowledge and awareness on to others, it will be so helpful. We need to work with our health department and council to see what support they can provide for us.

- Health authority and Councils – Collaboration, Relationship building

Some people don't understand the seriousness of living with these challenges. They think; you're on medication and your fine. Our health offices in our communities don't know what I'm going through, or how hard it is. They don't understand why we are asking for their help. I would like information put together for our care givers, our council, those people who really don't know what people in the communities go through when they are sick. This information would help them understand that we do need their help, that Elders need the support. The health authority doesn't understand how the people that they're helping are feeling, what they're going through. If our own workers in our communities don't know the needs of the people, how would they (health authority leaders) know? We need to get something written point by point about heart failure, and what it is like to live with this, in a simple form that they'll read.

- Information for health care professionals
- Information for health care leaders
- Advocates
- Driving change

Appendix L

Utilizing Greenwoods Framework for Analysis

1. What are the experiences of Indigenous women diagnosed with heart failure?

How do they manage living with HF?	***What determinants impact the ability to live well with HF?***	***What has been the experience with the Health Care System?***
STRUCTURAL (Legislation/policy/agreements)	**STRUCTURAL** (Legislation/policy/agreements)	**STRUCTURAL** (Legislation/policy/agreements)
• FNHA perspectives on health and wellness • FHNA as a wellness partner documents • FNHA funding for prescription medication • UNDRIP – Article 11&15; Practice and revive traditions and customs. Article 24; Right to best health and traditional medicine/healing • TRC Call to Action 22; Value of healing practices	• Canadian Cardiovascular Society HF guidelines- push triple therapy and SM education. • Canada Food Guide recommendations privilege Western beliefs • HCS policy and structure favors biomedicine • FNHA not funding IP living in urban centers/not within communities/nations • TRC Call to Action 18; Health of IP linked to colonization	• Cultural safety and competence policies – BCCNP, CNA, IHA, FNHA, BC Association of Aboriginal friendship centers • Health transfer policy doesn't fund traditional healers • IHA letter of understanding and partnership accord with 7 nations • IHA Aboriginal wellness strategy – Equity and cultural competency • TRC Calls to Action 19; Measuring and reporting outcomes to identify and close gap in health inequities. Call to Action 22; Role of and need to collaborate with Elders/traditional healers. Call to Action 23; Cultural competence

How do they manage living with HF?	***What determinants impact the ability to live well with HF?***	***What has been the experience with the HCS?***
SYSTEMIC *(Education, health, justice. Organizations/programs/services)*	**SYSTEMIC** *(Education, health, justice. Organizations/programs/services)*	**SYSTEMIC** *(Education, health, justice. Organizations/programs/services)*
• Advocates • APN program in IH hospitals • Services for families • Services within communities • Community led services • Services based in traditional knowledge • Virtual services	• Lack of access to services – distance, time, cost • Food insecurity • Lots of appointments • Move away from community • Nurses as educators – skills to teach patients. Health literacy and learning style assessments • Belonging – RS, Ministry home, foster care • Biomedical model focus on CDSM, ignores other beliefs about wellness	• Indigenous hcp • HFC structure around clinic needs not patient needs • APNs • Inconsistent information • Teaching material lacks cultural reflection • Language privileges biomedical model and power of hcp • SM focus of interaction in HFC • Cultural safety training/education
How do they manage living with HF?	***What determinants impact the ability to live well with HF?***	***What has been the experience with the HCS?***
SERVICE DELIVERY *(Cultural safety/Individual)*	**SERVICE DELIVERY** *(Cultural safety/Individual)*	**SERVICE DELIVERY** *(Cultural safety/Individual)*
• Holistic approach – emotional, spiritual, mental, physical • Healthy foods • Activity • Ceremony • Connection to the land • Traditional healing • Rest/Sleep • Talking as therapy • Support from families • Self-reliance • Positive attitude • Self-monitoring • Feeling informed and understanding what is happening	• Lack of Information • Understanding health related teaching/information • Relationships with hcp • Stress/Grief/Trauma • Multiple conditions/symptoms • End of life conversations • Side effects from/ concerns with taking western medication • Multiple social roles – parent, grandparent • Health concerns of other family members • Self-perception/body image • Pandemic impact	• Lack of consent • Stereotyped • Marginalized • Racism • Disrespected • Dominant agenda of biomedical model • Feeling rushed • Not listened too • Terminology • No reflection of culture • Relationship with hcp – trust • Long hospitalization • Virtual care

	• Living alone • Emotional/mental health – overwhelmed, scared, worried • Pain • Moving away from home nation/community • Family not able to support/Don't want to burden	

2. What programs and services do Indigenous women living in the interior of BC need to live a healthy life with HF?

STRUCTURAL (Legislation/policy/agreements)	**SYSTEMIC** *(Education, health, justice. Organizations/programs/services)*	**SERVICE DELIVERY** *(Cultural safety/Individual)*
• ***Global & Federal*** TRC Calls to Action 19 (closing gap, measuring outcomes), 22 (Elders/traditional healer), 23 (Cultural competence and Indigenous hcp), 24 (Nursing schools) UNDRIP Articles 15 (practice and revive cultural traditions), 18 (participate in decision making), 20 (Institutions), 21 (Improvement to DoH), 23 (Involved in determining and developing programs), 24 (traditional healing and right to best health) CIHR (2019) Strategic Plan: Setting New Direction – Focus on supporting Indigenous research, IP setting priorities and leading. Decolonizing, Building relationships, accountability, trust • ***Provincial*** Transformative Change Accord (2005); Increase in Indigenous hcp, programs directed by needs of IP, chronic conditions, access	• Funding from health authorities for local support group programs • Resources for cultural safety education for hcs leaders and individual hcp • Education system – supports for IP to access higher education/nursing program/medical school • IH Aboriginal wellness to develop IP specific educational material • BC PHSA and BC HFN to create IP specific resources with input from nations and communities • Funding to enhance APN program to out-patient services	• ***Services and support groups within communities*** Locally led Not focused on medication/medical treatment but on living and coping with health challenges within an Indigenous context Traditional knowledge • ***Information for HCP*** Build understanding for hc leaders about what is needed for patients • ***Information for patients*** Recipes Information about what it's like/women's stories Traditional foods and medicine • ***Advocates*** Within the HCS – Indigenous HCP Within communities – Nurses, support people Supporting families • ***Cultural competency*** Enhanced training for HCP

to primary care, cultural competency FNHA funding policies • ***Municipal/IHA*** IHA Health and Wellness Strategy – 4 priorities, include cultural competency, participation in decision making, improve health equity, improve wellbeing		