

THE DECISION MAKING PROCESS ABOUT TREATMENT FOR INDIGENOUS WOMEN
WITH BREAST CANCER FROM THE CANADIAN PRAIRIES

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By

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ABSTRACT

This qualitative study focuses on the decision-making process that Indigenous women undergo when receiving breast cancer treatment. The main research question is: how do Indigenous women with breast cancer make decisions around cancer treatment? One-on-one, open-ended interviews were completed with 12 Indigenous women from the Saskatchewan region. A lens of two-eyed seeing was applied, which means that participants were expected to view their life from a traditional or western perspective, or a combination of the two. Four main themes were identified: socioeconomic status, accessibility, culture, cultural safety, and led to women-informed recommendations.

Socioeconomic status had three main subthemes of everyday responsibilities, poverty, and medical accessories. Accessibility included three subthemes of knowledge, location, and travel. Culture consisted of two main themes of diversity and stigmas around the disease, with diversity including traditional, western, and two-eyed seeing and stigmas around the disease being mostly related to silence around cancer. Cultural safety included influences from the Indian Residential Schools, feeling like a stranger in the healthcare setting, communication, time, connecting, and self-efficacy. Women-informed recommendations are based on suggestions the women gave regarding aspects related to their treatment choices that they would have liked to have been done differently. The findings from this study will be used in the future for knowledge dissemination, transference, and application.

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Thank you to Dr. Sarah Oosman, as the external examiner, who offered insightful recommendations and was an excellent person to have on my committee. Being an Indigenous health expert, she informed me about properly bringing together the processes of decolonization and Indigenization to reach a state of reconciliation.

Thank you to Lorna Arcand for participating in this project and recruiting every single participant who was willing to allow their stories to be heard. You not only allowed me to hear your story, you also allowed me into your community and welcomed me into your culture through events such as the sweat lodge ceremony—a place of spiritual healing and humility. I will never forget that, and the wonderful person that you are. This literally could not have been done without you. Hai Hai!

DEDICATION

This project started when I was an undergraduate student living with an Indigenous family in Peguche, Ecuador and I realized how privileged I was being a Caucasian woman from Canada. It was a small moment when I was alone with my host mother on a bus ride into the local town where she confronted me about some of the domestic abuse that occurs within her community. I wanted to help her but I was not sure how. I was only 23 years old at the time and in a foreign land. As a way to use the power I had, the privilege I had, to shift the power or at least inform the general public about some of these injustices, I realized the first thing I had to do was listen. By listening, and not just acting, I had to actually hear what my host mother was saying, and try to empathize and understand her situation.

Many overlapping power structures affected her situation. State and political structures and state laws did not protect women from abusive husbands. Economic and familial structures bound women to a certain place in the household. On top of that were cultural influences that deterred women from speaking out about these issues with loved ones. It was frustrating and sad to hear about these traumatic situations with which this Indigenous community was struggling. I felt like I had no power in the situation yet I was very happy she could speak openly to me about these issues. I was someone who only a few weeks earlier was a complete stranger, yet I had built trusting relationship with her by living in her home and doing similar daily activities, such as making breakfast, caring for her four children, buying food at the market, walking everywhere as a means of transportation, preparing lunch for her children after school, hand washing the laundry and hanging it out to dry, taking their eldest daughter into town for additional English classes in the evenings, weaving and pressing cloth materials in a shack in their yard for some

additional income, cooking supper for the family in the evening, and eventually getting ready for bed.

Fast forward three years and I am back home in Canada completing my degree. I knew I had a passion for understanding Indigenous issues, especially those related to women, and I wanted to focus my Master's thesis on furthering my understanding, but in a local context. I happened to be on a research team the summer prior to my graduate degree program, during which time some doors opened up for me in terms of networking with those interested in the field. Dr. Gary Groot, a man I heard only good things about, was working on understanding Indigenous women's decision-making processes when going through breast cancer treatment. I knew right away that the project was something I could excel in and I met with him as soon as possible to begin this research.

During the summer of 2016, we started interviewing Indigenous women across the province, and I started learning more about social, political, and economic issues that Indigenous women face in our country every day. I had this amazing opportunity to be let into their lives and had the honour and privilege to, again, hear about other Indigenous women's vulnerabilities, struggles, and lived experiences as marginalized peoples in our society; this is something I may never fully understand but can at least try to empathize and have compassion for.

During this time, I ended up having some issues with my own family: a brain cancer diagnosis in my paternal grandfather, someone who was very close to me and helped raise me in my younger and teenage years on the farm where we both grew up. I now had some personal experience to throw into the mix of my research journey, to further understand the horrors yet cohesiveness of a cancer diagnosis in one's family. I was terrified watching this once strong, able-bodied, and mentally determined man lose his will to live. He fought colon cancer five

years earlier and did not have the strength to go through another round of cancer treatments. I remember being very upset and feeling completely hopeless. The strange thing of it all was that I was currently doing research in this field and I felt more lost than ever.

Why was I doing this work if we did not even know the cause of cancer? Why have we not figured that out yet? How many more people have to die this way before we would get to the root cause of the issue? I went from upset, to helpless, to frustration, to anger, to cynicism. I even had thoughts of going to go live in the bush because I started to believe that society's current way living must have been the creation and expansion of this cancerous growth on us all. I believed that cancer must thrive in our hectic, crazy lives: a place where work and money dominate our every decision, even to the point where they take over our most intimate connections to family, friends, and the environment. Perhaps it was caused by our poor diet? I kept hearing about how sugar is the number one ingredient causing cancer to thrive in the body. Then I thought maybe it is all this new technology all around us 24/7—the Wi-Fi, the cell phone towers, the electrical outlets, the high energy light bulb. Maybe it is all the pollution humans have already done to this planet? Perhaps it is some kind of karmic cycle where we forgot to be thankful and respectful in the way we live our lives and survive on this planet, so it is not just God's choice to punish us for all the chaos we have created but also Mother Nature who we have harmed and abused for so many years.

I am sure it could be proven through science if we measured some of the toxicity in the water we drink, the air we breathe, and the soil we use to grow our food. But then I had to contemplate, what then? What if it is proven? How do you change a system that is in full swing of continuing the harm, relying on the economy for all of its answers? I also think about how my grandfather was a farmer, how did he get cancer? Sure, he liked to smoke tobacco but he was not

a big drinker, he most often ate home cooked meals, and was rarely surrounded by urban pollution. I also think of his father, my great-grandfather, who smoked more than he did, drank, and consumed so much salt every meal that he had his own personal salt-shaker at the kitchen table; yet, he lived to be over 100 years old. My grandfather died at 82, the night before my 27th birthday, and I cannot help but feel like I have disappointed him. I never gave him any grandchildren. I am not married or even engaged. I have yet to complete my education and have barely began my career. When he was my age, he was married, owned the homestead farm with seven quarters of land, and had four children. What have I done that is meaningful? What will I have to show for myself when I am gone?

Throughout this journey, I have learned a lot about myself, my family, and my position in this world. I have decided that this book, this work, will be a part of my legacy—something I want to give back to the community. It is not something I want personal recognition for, but it is a small part of a bigger puzzle to which I want to contribute: a movement that will shift our way of viewing the world. I want this work to be a part of that shift, and I think it already is happening. I also cringe at the thought that this will sit on a shelf and collect dust. I do not want to do that either. I want this work to be meaningful and progress into something even greater and more powerful than I could ever imagine.

As I have heard before, cancer knows no age, no race, no religion; it can take any one of us at any time, even animals and children. We need to work together to move on from it. If we cannot conquer it, we need to know how to at least deal with it in the most positive and informative way. I learned from my grandfather that we cannot just talk about things: we need to take action, we need to do something. This is my action and this is the role I have been given right now. I do not need to identify as an Indigenous person to understand their struggle, to hear

them out, to listen to their stories, or to work with them to make better changes for us all dealing with cancer while going through the healthcare system.

I want to dedicate this work to Martin Hetzel: the most determined, observant, and compassionate animal lover I ever knew. May your new journey be everything you ever wished for and more.

PREFACE

This study began to take shape when Dr. Gary Groot, the Principal Investigator of this study, a cancer researcher at the University of Saskatchewan, and a general surgical oncologist in the Saskatoon Health Region, wanted to address a significant gap he recognized in providing care for Indigenous peoples who have entered the healthcare system. Dr. Gary Groot began his medical career at the age of 24 in Africa, in what was then Zaire and is now the Democratic Republic of Congo. His experiences there taught him a lot about the importance of perceiving health from differing cultural knowledge systems and the way that they relate to a community's health status. He also learned a lot about his level of privilege in this world through his integration with the Zairian people and how powerful, yet challenging, that privilege can be; at times it was uplifting and at others it was isolating. He now uses his knowledge and experience to try and bring together different understandings of healthcare to achieve the most optimal level of care for his patients. In this study, he focuses on gaining a deeper understanding of the shared decision-making (SDM) process that Indigenous women experience when going through cancer treatment by conducting one-on-one interviews with 12 Indigenous women from around Saskatchewan.

Dr. Rose Roberts is a nurse educator who works at the University of Saskatchewan. She joined our research team in early 2016. Roberts wrote her dissertation, called "*Cancer Stories from the Woodland Cree: Exploring Perceptions of Cancer, Health, and Illness in Northern Saskatchewan, Canada*", in 2009. Roberts is a Woodland Cree who grew up in Stanley Mission, Saskatchewan and whose mother was diagnosed with cancer. Roberts holds a Bachelor of Nursing degree as well as Master's and Doctoral degrees in Community Health and Epidemiology from the University of Saskatchewan. She strives to find a balance between the

two worlds, of Cree and western traditions, to create change in cancer care protocols. In this study, Dr. Roberts assisted Dr. Groot throughout the data collection phase (interview process) by helping him conduct the interviews.

Chanda Hetzel is a Master's student from the Department of Sociology at the University of Saskatchewan. She began her interest with this research when she volunteered abroad for eight weeks in Peguche, Ecuador and lived with an Indigenous Quechua¹ family. This initiated her passion to learn more about Indigenous health, noticing an issue of domestic violence towards Indigenous women in that region. Due to the experiences and excitement she got from building relationships in Ecuador, she decided to apply her knowledge and passion for Indigenous health to a local context within Canada. When she heard about Dr. Groot's project, focusing on Indigenous women with breast cancer, she knew that this was the perfect opportunity for her to build her knowledge and increase her awareness around social issues Indigenous women are facing within Canada—a pressing issue today. Dr. Groot completed some of the ground work prior to her joining and had intended to conduct the interviews personally with the help of Dr. Roberts. Hetzel was invited to be present during the interviews with the permission of the participants. To respect of participants' confidentiality, she primarily focused on the data analysis. She also thoroughly enjoyed getting more involved with the Indigenous community in her area (Saskatoon), including building relationships with the Elders, going to culture camps, participating in pipe and sweat lodge ceremonies, and visiting with Indigenous community members at academic conferences.

¹ Quechua refers to the Indigenous group of native peoples who reside in South America, predominately in Peru, Ecuador, Bolivia, Argentina, Chile, and Colombia. (155)

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Chapter 1: Beginning the Research

1.1 Introduction

This thesis shares the stories of 12 Indigenous² women living within or near the Saskatchewan region who have a history of breast cancer. The purpose of this thesis is to understand how Indigenous women with breast cancer are making decisions about their treatment options. Using the theoretical framework of decolonization and a lens of two-eyed seeing, the analysis identified common themes in their stories. The data suggests that while the women had diverse experiences in their breast cancer journeys, and had many different treatment preferences, they shared similar experiences of feeling a lack of support for Indigenous women in the healthcare setting. More specifically, the women identified several key concerns that shaped their experience about decision making in their breast cancer treatment. These include 1) their socioeconomic status, 2) their accessibility to health care services, 3) their cultural identification, and 4) cultural safety. These themes then guided recommendations for positive change for Indigenous women with breast cancer in health care settings.

² The term Indigenous peoples refers to any native born individual who has along settlement and connection to specific lands and who has been adversely affected by incursions by others including industrial economies, displacement, and settlements in their Traditional territories. (158)

1.2 Purpose of the Study

The purpose of this thesis is to understand the factors that impact the decision-making process that Indigenous women from the Canadian Prairies with breast cancer make about their treatment. Although there is a the lack of statistical data based on ethnicity in Canada's healthcare system (1–3), current data indicates cancer rates in Indigenous communities are increasing (4–6). More specifically, breast cancer rates for Indigenous women are rising faster than for non-Indigenous women. (1) In Saskatchewan, Indigenous women are more likely to be diagnosed at a later stage in the disease and have higher mortality rates than non-Indigenous women (1,5–7), even though they are diagnosed with breast cancer at about the same rate (4,6,8). This issue is particularly prominent for Indigenous women in the northern part of Saskatchewan. (5,6)

Indigenous women's lived experiences encompass aspects of cultural, social, political, and economic realities; however, there is a gap in the literature with respect to how their experiences are understood with respect to decision making about breast cancer treatment. (9–11) One important aspect is understanding the role of culture in the consideration of traditional and western perspectives related to cancer, and its treatment, in order to create proper interventions to improve cancer survival for Indigenous populations because these can largely influence their medical decision making processes. (12) Furthermore, scant research explores decision making about breast cancer treatment for Indigenous women from the Canadian Prairies. A more in-depth qualitative study is necessary to further explore this phenomenon because qualitative methodologies are appropriate when limited information is available on a topic. By focusing on the participants' experiences with breast cancer, we can contribute to

understanding the complex decision making processes for Indigenous women with breast cancer in this region. (13–15)

1.3 Research Question

Given the lack of research in this area, the following research question and two sub-questions frame this study:

What factors influence Indigenous women with breast cancer from the Canadian Prairie region to make decisions about cancer treatment?

- 1) What roles do culture, social support, community, access to health care, and their relationships with health care providers play in their decision making process?
- 2) What recommendations do these Indigenous women suggest for improvements in support for breast cancer treatment in health care settings?

1.4 Theoretical Framework

This research is undertaken with a decolonizing framework of two-eyed seeing to better understand Indigenous women's lived experiences within society, and how that shapes their decision-making process about breast cancer treatment. A decolonizing framework highlights the impacts of colonization as well as the resilience and restoration of Indigenous values, practices, and beliefs.(16) A decolonizing framework is reflected within the research throughout both the data collection and analysis phases, where the women were the main educators and their lived experiences with breast cancer was the main data source.

Two-eyed seeing is a way of envisioning the world from both Indigenous and western perspectives of health and healing. In this case, it refers to how the women view their treatment plans based on their own personal beliefs of what cancer is and how to treat it accordingly. It is important to encompass both viewpoints, as well as a combination of the two, because the

women lived their everyday lives “in both worlds”. Most women have strong influences of western culture in the way they were raised. At the same time, they still choose to maintain their sense of Indigenous identity by integrating aspects of both belief systems into their treatment plans.

Cultural safety is a second concept framing the research. Cultural safety is a lens through which health care practitioners can see their patients with knowledge about the history of colonization and the way it shapes Indigenous people’s thoughts, experiences, and wellness. It was developed in New Zealand in the 1980s within the Maori population due to high levels of dissatisfaction with nursing services. (17–20) Initially it was created as an educational model or lens to address power relationships between healthcare professionals and those they serve (19), to create a more inclusive understanding of the patients’ lived experiences. This concept places emphasis on the importance of healthcare professionals acknowledging their own power through social, political, racial, and economic contexts and understanding the importance of patients’ as knowledge holders. Indeed, a culturally safe health care setting would provide more effective and holistic care for Indigenous women.

1.5 Research Methodology

Between December 2015 and August 2017, 12 Indigenous women from the Canadian Prairie region (Alberta, Manitoba but primarily Saskatchewan) were interviewed in face-to-face, open-ended interviews with Dr. Groot, Dr. Roberts, and myself. Dr. Groot was the main interviewer. As the Principal Investigator and practicing oncologist, it was very important to him that he lead the interviews so he could make direct connections with participant women which would enable him to build ongoing relationships with them. Dr. Roberts, as a community health nurse researcher and with great experience using Indigenous methodologies, was also invited to

participate in interviews and conduct a narrative analysis of the data. While Lorna Arcand did not conduct the interviews herself, she acted as the main Community Liaison enabling us to meet each of the women. Finally, I was involved in the interview process, mainly as an observer and student researcher to better understand the research process and make connections with participants, including taking field notes throughout the study.

The participants were interviewed by inviting them to tell their life story in relation to their breast cancer experiences. This helped to gain a deeper understanding of how treatment decisions were formed and what role social support, community, access to health care, and their relationships with health care providers played in their decision making process. The interviews were analyzed using a decolonizing framework that allowed us to address the cultural, social, political, racial, and economic contexts where the women's experiences were valued as the main source of knowledge.

1.6 Overview of the Thesis

This thesis is divided into six chapters outlined here. In chapter two, I outline the literature review and recent work in the field. The literature review includes information about: breast cancer rates, Indigenous women's health, Indigenous women's experiences with cancer, Indigenous perceptions of health, Indigenous medical decision making, and Indigenous women's decision making process about breast cancer. The theoretical constructs of decolonization, two-eyed seeing, and cultural safety are discussed as well. This literature review provides a context to better understand the unique perspectives of Indigenous women with breast cancer from the Canadian Prairie region.

In chapter three, I discuss the research methodology including the main research question, the recruitment process, and sampling technique. Rigor and ethical considerations are

outlined, as well as the research design. The research design includes the interview protocol, and main steps used during the interpretative thematic analysis (ITA).

In chapter four, I introduce the women using pseudonyms then describe their cancer diagnoses and individual identities as well as their treatment choices, main concerns, and outcome of their cancer experiences. I also provide a chart at the end of the chapter of the women who participated in the study.

In chapter five, I summarize the main themes of their: 1) socioeconomic status, 2) access to health care services, 3) relationship with their defined culture, and 4) cultural safety or their feelings of support in health care settings. Socioeconomic status discusses how income influenced their decision making process. This includes their: 1) everyday responsibilities, 2) level of poverty, and 3) expense of medical accessories. Accessibility to health care services plays a role in their decision making process, such as: 1) their knowledge about the disease, 2) their location in relation to a health care centre, and 3) difficulties travelling for medical services. The relationship the women have to their culture shaped the women's decision making process. The women identified that: 1) their diverse perspectives of cancer (western/traditional/both), and 2) stigmas around the disease influence their cancer treatment decisions. Cultural safety, or feelings of support in health care settings, assists the decision making process. The women discussed these main aspects when being treated in health care facilities: 1) their experiences with Indian Residential Schools, 2) feeling like a stranger in the health care setting, 3) communication differences, 4) lack of quality time, 5) connecting as a source of empowerment, and 6) their level of self-efficacy.

In chapter six, I mention the women-informed recommendations which are suggestions of change in the health care system from the women themselves. These included a need for:1)

culturally appropriate care, 2) an option to have a female doctor when requested, 3) Elders and nurse navigators present at health care facilities, 4) Indigenous-based health education materials in health care settings and Indigenous communities, 5) further research on the benefits of traditional medicines used for cancer, 6) simply being asked, as a patient, what their beliefs are ,and 7) using the internet as a source of education and networking with other Indigenous women afflicted with breast cancer.

Chapter 2: Literature Review

2.1 Introduction

This literature review includes information about breast cancer, Indigenous women's health, Indigenous women's experiences with cancer, Indigenous perceptions of health, Indigenous decision-making, Indigenous women's decision-making about breast cancer, and recent work in Saskatchewan related to patient-centered care. Also, theoretical frameworks of decolonization, two-eyed seeing, and cultural safety are discussed. This literature review helped to understand the unique perspective of Indigenous women with breast cancer from the Canadian Prairie Region.

To provide some context, Saskatchewan has the second largest population of Indigenous peoples³ in the country, next to Manitoba, at about 15% of the population.(21–23) A total of 70 First Nations groups are present in the province, with 63 affiliated with one of the nine Saskatchewan Tribal Councils.(24) The five linguistic groups of First Nations in the province are Cree, Dakota, Dene (Chipewyan), Nakota (Assiniboine), and Saulteaux.(24) Saskatchewan has the most treaty areas of any province at six, specifically treaty areas 2, 4, 5, 6, 8, and 10.(24) Research in Saskatchewan is especially important given the large population of Indigenous peoples in the province.

2.1.1 Breast Cancer Rates

In Canada, approximately one out of every nine women will develop breast cancer in their lifetime. (25) According to the Canadian Breast Cancer Society in 2015, one in thirty women are at risk of dying from breast cancer and it is the second-most common cause of cancer

³Indigenous is an international term used to identify First Nation inhabitants (referred to in Canada as "Aboriginal", "First Nations", "Métis", or "Inuit"), indicating they are the original inhabitants of the country or descendants of the original inhabitants of the country.(32,56)

related deaths after lung cancer. (25) Estimates suggest 750 new breast cancer cases for females and 160 deaths from breast cancer in Saskatchewan in 2017. (26)

Although no policies are currently in place within Canada's healthcare system to accurately track patients based on their racial status (1–3), current data indicates the incidence of cancer in Indigenous communities is increasing. (4–6) Breast cancer rates for Indigenous women are said to be on the rise. (1,4,6,27) In Saskatchewan, Indigenous women are more likely to be diagnosed at a later stage in the disease and have lower survival rates (1,4–7), despite current health rates showing that Indigenous and non-Indigenous women are diagnosed with breast cancer at about the same rate. (4,6,8) Although statistics show higher rates of mammogram screening amongst the Indigenous population, compared to previous years, they are still presenting at a later stage in the disease. (28) This is particularly prominent for Indigenous women in the northern part of the province whose survival rate from breast cancer is lower compared to southern non-Indigenous women. (4–6) Previous work suggests that women in rural/remote locations are more likely to be at risk of breast cancer due to an "...early onset of child bearing, a higher number of pregnancies, poor nutrition, relatively poor health, and inconsistent or non-compliant follow-up of cancer screening tests". (28)^{pp.281}

The disproportionate rates of cancer in Indigenous and non-Indigenous populations have been linked to "... age at diagnosis, spread of the disease at diagnosis, comorbidities, medical treatment received, socioeconomic disadvantage, and access to healthcare." (29)^{pp.1} These disparities might also be due to a greater chance of being diagnosed at a more advanced stage in the disease, delayed diagnosis, incomplete treatment, a decision for non-invasive treatment, impacts of colonization, and inappropriate care given in healthcare settings. (30–32) Indigenous peoples being diagnosed at a later stage in the disease has been linked to low awareness of early

symptoms, tardiness seeking medical advice, poor access to healthcare services, and nihilist beliefs about a cancer cure. (33) Some folk and religious beliefs, such as traditional Indigenous views of cancer, are seen as fatal and have been linked to breast cancer being diagnosed at a later stage in the disease due to a lack of screening practices.(31,34–36) Cross-cultural examinations indicate age, family history, reproductive history, level of education, and alcohol intake do not statistically influence breast cancer incidence. (37) This suggests that social, political, and economic factors play a more important role in breast cancer incidence and survival than biological predispositions. (34,38) Improving access to care, addressing different patient preferences for treatment options, and respecting Indigenous patients' cultural beliefs have been suggested as ways to improve cancer survival rates. (12)

2.1.2 Indigenous Perceptions of Health

When supporting Indigenous patients, it is important to keep in mind the cultural differences in the way health is defined. (39) It is also essential to acknowledge the role that colonization may play in the lives of Indigenous peoples and the diversity amongst this group. Historical trauma has been experienced by this population, and is defined as the collective, emotional, and psychological wounding that spans across generations and has cumulated over time. (40) Indigenous perspectives of health and healing can be diverse and feature components of western ways of medicine and traditional ways of healing. (41) Although Indigenous medical systems can largely be distinguished "...by oral traditions, distinct languages, the importance of community, and the view that human health is interconnected with the earth". (42)^{p.2}.

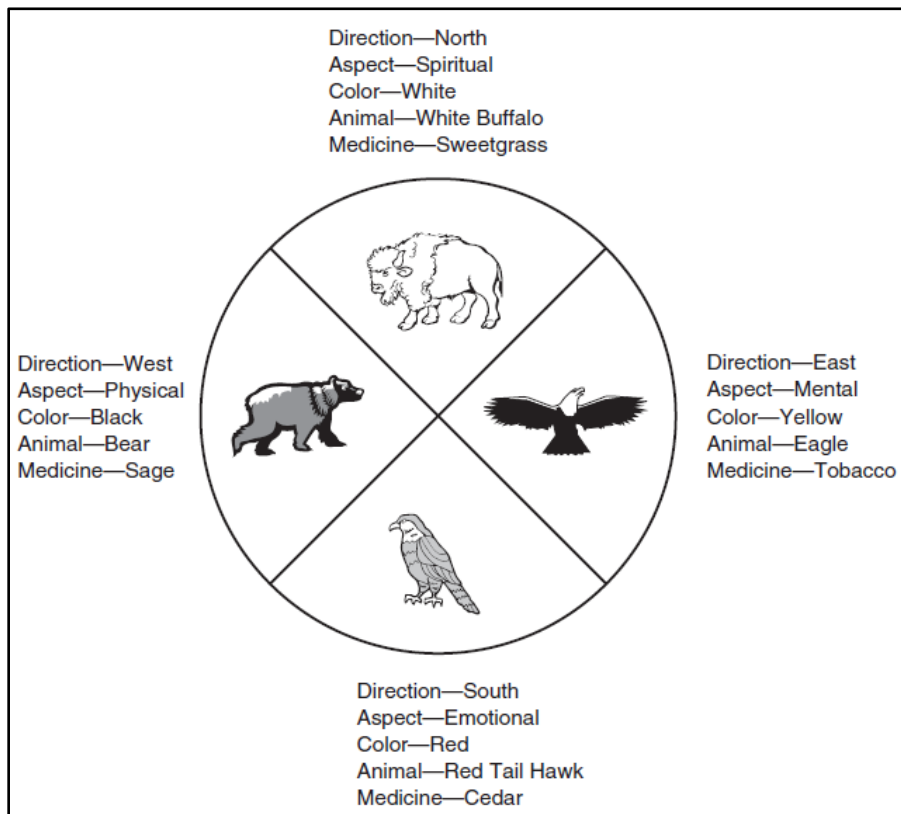
Some Indigenous people's viewpoint on health has been described as holistic in nature and includes physical, mental, emotional, and spiritual aspects of the self that need to be balanced for an individual to be considered healthy. (35,43–47) This has often been portrayed

through the medicine wheel, which is a diagram of a circle separated into four quadrants representing the different aspects of our physical reality as well as symbolizing the four seasons, four directions, four sacred animals, four medicinal herbs, four human races, four main colours, four aspects of the human self, and four main stages of the life cycle.(44) Disease and illness are said to come into one's life when these four parts are no longer in balance.

Figure.1: Medicine Wheel

Dapice AN. The Medicine Wheel. J Transcult Nurs. 2006;17(3):251–60. Figure 1. The Medicine Wheel; pg. 252.

Studies in medical anthropology also suggest that becoming healthy from an Indigenous perspective is sometimes referred to as a transformation, rather than the absence or removal of a disease or illness. (48) These differences in understanding diseases, such as cancer, could stem



from traditional Indigenous belief systems. For example, some Indigenous cultures view serious illness, such as cancer, as manifesting itself into one's life simply by talking about it aloud with other people. (14) However, some Indigenous peoples have little interest in viewing health from a traditionalist standpoint and are mainly concerned with how western medicine can heal their cancer. (41,49) For example, a study by Canales found that Indigenous women in the United States who felt their situation was serious or life-threatening were more inclined to seek western medical treatment for their breast cancer. (50)

Some barriers related to Indigenous cancer care are rooted in the differences between these belief systems. There are deep-seated biases as to how non-western medical systems were created and how they can best be understood within our current healthcare system. (51) Research in this area is vital for our current healthcare system to expand its current understanding of health. Health, in Indigenous communities, is ingrained in social, political, and economic influences and must be understood from historical, local, and continually shifting schemas. (52) It must first be built upon Indigenous worldviews, epistemologies, and cultures.

Communication issues can also arise due to cultural differences of health, wherein Indigenous perspectives of health can be quite different than western perspectives of health. An example of a systematic barrier is physicians having poorer communication with minority patients, which can lead to greater health disparities amongst this population. (53) This is often due to differences in cultural understandings of care. Although western and Indigenous knowledge systems vary significantly, Indigenous patients are more likely to view their healthcare as coming from two-world views where traditional and western treatment options are taken into consideration during the decision-making process. (40) This can be better understood as a spectrum wherein some

Indigenous patients will want a varied amount of traditional or western medical treatment options.

2.1.3 Indigenous Women's Health

Despite Canada's universal healthcare system and high standards of living, Indigenous populations, as a whole, are more likely to have lower health status and encounter more barriers when accessing quality healthcare.(54) Social determinants of health are the conditions into which individuals are born and include social factors that influence their health, such as housing, education, employment opportunities, and accessibility to appropriate healthcare services. (2,55) Indigenous women, in particular, are more likely to experience a disproportionate level of ill-health compared to Indigenous men and other Canadian women. (10,13,56–58) Indigenous women are one of the most vulnerable and marginalized populations⁴ in Canada (10). Canada's dark history of colonial policies, such as the implementation of the Indian Act (1867) and other colonizing practices post-European contact have left Indigenous women particularly vulnerable, because these actions were intentionally geared at disempowering Indigenous women and their communities. (16,52,59) The mainstream healthcare policies in Canada have reflected "...a century of internal colonial politics that have effectively marginalized Aboriginal (*sic*) people from the dominant systems of care". (60)^{p.126}

Indigenous women were first disempowered when they were traded as commodities throughout fur trade agreements when European settlers initially came to Canada. (61) Then, when implemented, the Indian Act banned them from obtaining status rights if they were married to a non-Indigenous man (this has only recently changed in Canadian legislation). (27,59,62,63) Next, authorities came and took their children away, forcing them to go to Indian Residential

⁴Marginalized populations refers to groups of people who are vulnerable due to genetic, cultural, social, political, and/or economic situations; their status has an immense impact on healthcare delivery. (145)

Schools (IRS) where there were high rates of physical, mental, emotional, spiritual, and sexual abuse towards the children, as well as an intergenerational effect on Indigenous families. (11,64)

Historical experiences of colonization still affect some Indigenous patients today. In the past, Indigenous peoples feared that doctors were involved in a plot to kill them as part of a government plan.(53,65,66) According to Cheryle Partridge, "...the goal of residential schools was institutionalized assimilation by stripping Aboriginal peoples of their language, culture and connection with family". (67)^{p.34} By the 1960s, more authorities came and decided Indigenous families, in particular mothers, were unfit to raise their own children; therefore, children were taken away and placed into the child welfare system; this initiative is known as the "sixties scoop". (68) Today, Indigenous women are one of the largest populations represented in Canada's missing and murdered case files. (69,70) It comes as no surprise that many Indigenous women in Canada have difficulties trusting the government, or other members of authority, when they have been marginalized and systematically discriminated against for so long. All of these historical influences of hardship between Indigenous peoples and the nation state continue to influence this population in terms of health, social, economic, and political disparities. (56)

Because Indigenous peoples have a history of being marginalized within Canadian society, it is understandable that they struggle to communicate, build trust, and confide with their healthcare providers when seeking breast cancer care, and making decisions regarding a life-threatening illness. One may argue that this occurred many years ago and cannot be relevant to Canadian society today. However, many discriminatory policies were only recently revoked; for example, the last IRS in Canada (in Saskatchewan) was closed in 1996 (71,72) and, as such, family dysfunction, increased substance/alcohol abuse, and high unemployment rates amongst this population remain. (72) This is why creating culturally appropriate models of care that are

sensitive to Indigenous women's experiences, is an essential step in adopting a plan that is suitable when dealing with Indigenous women with breast cancer. Specifically, there is a need to follow a decolonizing framework to make sure they do not become re-colonized during this process. Therefore, Indigenization of research protocols and de-colonization of these practices can lead to reconciliation.

2.1.4 Indigenous Women's Experiences with Cancer

Structural barriers and a history of colonization have been some major factors contributing to the health status of Indigenous women who experience cancer. (13) Encounters in the healthcare setting can also create a barrier for Indigenous patients seeking care. These encounters have commonly been defined as negative and linked to historical influences of oppression (20,55,58,73), such as "... loss of cultural and political institutions, colonialism, racism, and residential school experiences that had multigenerational impacts". (53)^{p.340} Some additional barriers mentioned in the literature include institutional racism (18,54,58,65,66,74–76), feelings of being a stranger or outsider in the healthcare setting, otherwise known as "othering" (1,18,56,74,75), a lack of cultural support within the healthcare system (18,54,76–78), limited accessibility to healthcare services for those living in rural/remote location (5,56,58,60,75,79), communication differences between healthcare professionals and Indigenous peoples (18,41,54,58,77), and higher rates of poverty or lower socio-economic status amongst this population (making time away from work or family for treatment very difficult) (21,77,80,81). The main barrier that encompasses all of those mentioned is the lack of understanding in Indigenous women's lived experiences by healthcare providers.(18,21,74–77)

2.1.5 Indigenous Medical Decision-Making Process

Differences in referral and treatment arrangements have been associated with a patient's racial or ethnic status. (77,82,83) This is, in part, due to differing cultural understandings of care, such as the unique perception of what health and illness is including how symptoms are recognized, to what they are attributed, and how they are understood; these factors all influence how and when healthcare services are sought. (82) These factors, along with many others, are the main reason why healthcare systems globally are moving towards a more patient-centered approach, meaning that healthcare providers focus more on the individual's healthcare needs rather than solely focusing on the disease itself, or making assumptions based on cultural generalizations. (84,85)

Isolation, unemployment, and lack of familiarity with the healthcare system has played a significant role for Indigenous patients compared to the general population when making healthcare decisions. (86) Indigenous patients have described feelings of mistrust and loss of dignity within social systems that were meant to support them. (73) Indigenous peoples have also described entering the healthcare setting as deeply connected to their collective history of colonization and how their ancestors were treated when seeking healthcare services, where the actual brick and mortar of the building reminds them of their experiences in Indian Residential Schools. (20) Because of this, the healthcare setting can feel like a foreign place where Indigenous cancer patients are likely to feel uncomfortable. (30) Discomfort in the healthcare setting becomes a major issue in the decision-making process because patients who do not feel respected or understood are more likely to remain quiet, refrain from asking questions, and withhold information from their healthcare providers. (87) This is very important because communication between patients and their healthcare providers is a large part of the decision-

making process and, when this is not done properly patients do not receive the level of care they need.

Healthcare decision-making for Indigenous peoples might involve consultation with community and family members prior to accepting treatment (40); this means that decisions for Indigenous patients who chose to do this will take longer because of this. Jonathan Ellerby and colleagues note that, "...for Indigenous people[s], decision-making is best understood as a process and not as a correct interpretation of a unified code". (54)^{p.846} Indigenous cultures are not paper-pencil oriented, so patients might not be as comfortable reading or filling out information in order to get services. (91) Conversely, some Indigenous peoples seeking cancer treatments from healthcare centres have also described a lack of structure, protocol, or procedure; as one participant in a previous study mentions, "...there's no protocol, of how to help a person die, or how to help a person heal". (88)^{p.18} Despite western medical institutions addressing normative decision models today as, according to Linda C. Garro, they are, "prescriptive [and] structuring in terms of probabilities and utilities [followed through in order] to reach an optimal decision". (89)^{p.323} Regardless of the healthcare system claiming to have proper structures and protocols in place, Indigenous patients did not feel this way when they were treated.

The maze of the medical institution can also be overwhelming due to having to follow so many policies and procedures, causing Indigenous peoples to avoid the healthcare system altogether, or leave before receiving treatment altogether. (2,90) Another thing to keep in mind is that some Indigenous patients might have an issue with advanced technology, which also has to be taken into consideration when discussing treatment options. (54)

It is important for healthcare providers to have familiarity with Indigenous protocols, to understand important customs such as the ethic of non-competitiveness, an attitude towards

gratitude and approval (41), as well as the cultural practice of non-interference, all of which are more prevalent in Indigenous cultures. (91) This can be achieved by simply asking what their cultural belief is so there is a better understanding for the type of care the patient wants. For example, non-interference is an important social principle, where a person who gives medical advice, such as a physician, is perceived to be an interferer attempting to establish dominance within the relationship. (91) When practicing non-interference, these power dynamics can be lessened where conversations around care become more of a discussion rather than a lecture. This practice might encourage Indigenous patients to be more open when communicating their values and beliefs, creating a better platform for patient-centered care to begin. Another important aspect of cultural care is to be mindful of the different styles of verbal and non-verbal communication. For example, speaking less and avoiding eye contact are viewed as ways of respecting members of authority in some Indigenous cultures. (92) Medical staff might view such behaviours in Indigenous patients as indicating disinterest in engaging in conversation or indicative of a lower level of intelligence; however, the behaviours might actually be a cultural practice of showing respect. There can also be an expectation amongst Indigenous patients that healthcare professionals will provide them with all the information needed without them having to request it. (87) These differences in cultural interactions might be why Indigenous patients are more likely to express concerns about their doctor being unclear or not providing full explanations of their conditions or treatment plan. (93)

Overall, misunderstandings between Indigenous peoples and healthcare staff, discrimination, lack of access to traditional medicines, lack of companionship in the healthcare setting, and feelings of neglect have all been described by Indigenous peoples in their experiences with Canada's healthcare system (58). These are some of the barriers that need to be

changed for Indigenous patients to engage more in medical decision-making. Improving medical decision-making interventions for Indigenous populations will best be achieved by engaging with their communities to create a process that is relevant and successful. (94)

2.1.6 Indigenous Women's Decision-Making-About Breast Cancer

Cancer treatment involves many difficult decisions that even the most trusting and medical-savvy patients can find overwhelming. (78) During the cancer treatment decision-making process, ethnic minority women and those of lower incomes, such as Indigenous women, are more likely to have low satisfaction or decision regret over their treatment choice. (95) This might be because Indigenous women with breast cancer have different experiences than non-Indigenous women with needing varying resources, types of support, and additional consideration regarding their historical background of colonialism. (14) Characteristics of women's identities such as race, class, ethnicity, culture, and sexual orientation add to the complexity of the interactions that take place between women, space, and place in healthcare settings. (96) For example, Indigenous women might not receive the care they need because they do not fit the role of the patient as the healthcare system is designed. (13) This means that the way health services are delivered instils the dominant culture's beliefs and practices onto Indigenous peoples without acknowledging their understanding of health and healing. (96)

Current models also fail to address the barriers Indigenous women face because they are not always the most appropriate for Indigenous patients, especially for those who are more traditional in their understanding of healthcare. For example, previous work in this area reports that "...misunderstanding, fear of death, fatalism, shame, preference for traditional healing, beliefs such as cancer is contagious and other spiritual issues affected their decisions around accessing services". (31)^{p.1} Furthermore, most Indigenous women who have undergone breast

cancer treatment did so because they believed strongly in their intuition and messages that their bodies were sending to them that something was wrong. (50) Communal life and social networks are used to support and guide healthcare decision-making, and have been proven to be key aspects used to improve Indigenous women's understanding and ability to deal with a cancer diagnosis. (28)

Some additional barriers during patient-doctor interactions have been identified by Indigenous women. Indigenous women diagnosed with breast cancer do not always understand what is being told or expected of them by their healthcare provider. (87) Indigenous women also fear not being intelligent enough in front of their doctors so often remain silent during patient-doctor encounters by not asking questions. (87) A previous study by Roanne Thomas-MacLean, Jennifer Poudrier, and Carolyn Brooks found that some of the key themes in Indigenous women's experiences with breast cancer included shame and silence, resilience and strength, as well as support. (14)

Previous studies have identified systematic barriers that highlight difficulties with "... the referral process, cost, availability of appointments and transportation, and issues with mammography equipment... [which all stressed the issue of]... how difficult it can be [for] the willing woman to obtain a mammogram [let alone someone who is hesitant of this process]". (35)^{p.383} Furthermore, women's beliefs and knowledge appears to have little to do with their decision to get a mammogram; however, a doctor's recommendation for one played a much bigger role in their decision to get screened for breast cancer. (34) Indigenous women might choose a mastectomy over lumpectomy to reduce the number of visits to the healthcare centre for treatment. (29)

Literature related to positive Indigenous patient experiences with health services highlighted being respected, understood, comfortable, and in control as the main aspects that supported them in the healthcare system. (87) For example, Indigenous women have described the ideal healthcare provider as someone who is sensitive and accepting of Indigenous women's lived experiences, "...compassionate, intuitive, respectful, respected by people in the [Indigenous] community, trustworthy, and having a good sense of humour. (76) ^{p.734} Patient comfort levels have also been demonstrated to increase with unexpected acts of kindness, genuine gestures of care, and engaging in opportunities to build long-term patient-physician relationships. (60,87)

2.1.7 Health System Structure

In 2002, Saskatchewan became the first province in Canada to establish a Health Quality Council (97) and, in 2009, took a "patient-first" approach in its redesign efforts. (98) Since then, the province's Ministry of Health has developed a patient- and family-centered framework (PFCF) that was implemented as a strategic plan across the entire healthcare system. (84) Shared Decision-making (SDM) is considered one of the key system-wide supports described in the Ministry of Health's appropriateness of care; this program originated in the Strategic Services Branch, for which Dr. Gary Groot is the clinical co-lead. Dr. Groot is one of the supervisors for this Master's thesis and helped to design this study to tackle some of the issues related to Indigenous health in this province, specifically related to cancer.

In 2016, the Ministry of Health and the College of Medicine partnered with other academic organizations and the Canadian Institutes of Health Research (CIHR) to establish the Saskatchewan Centre for Patient-Oriented Research (SCPOR). (99) SCPOR is where Dr. Groot received funding for his research in SDM. SDM in the context of Indigenous health is largely

unstudied, so Dr. Groot established a research team to further explore this area of health to understand how best to support Saskatchewan's Indigenous peoples in making their optimal patient-centered health decisions. The research team consists of Dr. Gary Groot, Dr. Rose Roberts, Dr. Jennifer Poudrier, Dr. Linda McMullen, Dr. Tracey Carr, Dr. Mary Hampton, Dr. Sylvia Abonyi, Dr. Gary Teare, Miss Tania Lafontaine, Mrs. Lorna Arcand, Mrs. Tamara Waldron, Mrs. Shelley May-Neufeld, and myself, Miss Chanda Hetzel.

Within the recent publication of the Truth and Reconciliation Commission of Canada: Calls to Action are seven calls to action in regards to health, such as recognizing and closing gaps in health outcomes between Indigenous and non-Indigenous communities, all of which align with this project. (100) The document particularly highlights number 22, which is a call for effective change in the Canadian healthcare system to recognize the value of Indigenous healing practices and using them in the treatment of Indigenous patients by collaborating with Indigenous healers and Elders when requested by Indigenous patients. (100)

2.2 Theoretical Frameworks

2.2.1 Decolonization

Decolonization is the process of revitalizing Indigenous ways of knowing, such as beliefs, practices, and values, through the recognition of colonizing practices on Indigenous peoples by bringing their perspectives to the center of the research project. (101) It also shifts, "...the focus from communities being researched to [one where they are] being collaborative partners in the research process". (102)^{p.273} This includes a more critical understanding of underlying assumptions, motivations, and values that inform research practices. (103) Decolonization "...has the potential to create change, enhance participation, and positively impact the health of Indigenous peoples through the understanding of honouring different perspectives of health". (102)^{p.275}

Social scientists and healthcare professionals must avoid endorsement of the monolithic view that the province's or country's Indigenous life is a single experience. (104) For example, women living in rural/remote locations might have different concerns than those living in urban settings. (76) Recognizing the diversity within Indigenous cultures is important (19) because how women identify as Indigenous varies amongst this population. (50) Postcolonial theorizing of Indigenous women in the past has wrongly assumed that this particular group has shared the same experiences of oppression. (62) For example, the postcolonial perspective of Indigenous women fails to understand the diversity, uniqueness, and alternative degrees of agency within this population. (62)

In this thesis, a postcolonial perspective is better to be replaced by a decolonizing one because the 'post-' implies that the colonial process is complete, which it is not. Linda Tuhiwai Smith explains this further by stating that the notion of *post* in "...'post-colonial' discourse, has

been defined in ways which can still leave out indigenous [*sic*] peoples, our ways of knowing and our current concerns". (16)^{p.24} Although, it has been argued that viewing health using a postcolonial lens is important given the larger social, economic, and political influences that shape women's health particularly in making sure that health disparities are not overlooked as behavioural, cultural, or lifestyle factors. (62) Furthermore, the complexity between power and knowledge is central to postcolonial theory and seeks to understand how western knowledge systems have constructed colonial ways of knowing. (105) I challenge this theory further and push it past understanding the deep-rooted colonial structures that dominate our society to one of a decolonizing perspective, where we are not only aware of this concept but reverse its effects and empower Indigenous belief systems to have equal credibility.

Indigenous health outcomes will only get better when Indigenous voices, opinions, and knowledge systems are used to inform policy, research, and service delivery for Indigenous people. (40, 13) For example, engaging with Indigenous communities and health program interventions that involve Indigenous peoples is vital to reduce cancer-related disparities within this population. (78,105) We know that raising awareness about certain health issues within Indigenous communities has led to increased social acceptability about the subject matter to the extent that community members are willing to take action on the perceived issue. (106) "We have the knowledge and the capability and the expertise". (76)^{p.733} For example, hearing other people's experiences can help individuals recognize treatment decisions more clearly by identifying the range of options available to them, what the alternatives might be, and generally providing emotional and/or social support that may be unavailable in other contexts. (107)

Researchers must understand Indigenous people's history by acknowledging that western research practices are also a part of colonialism. (43) Because research was often used to control

Indigenous peoples in the past, a decolonizing framework should be used when addressing issues related to health within this population. (43) This is because decolonization has the potential to empower Indigenous women, making it a very effective approach in addressing their healthcare needs. Indigenous women, themselves, provide a deeper understanding of the barriers that have been placed upon them; they know how to recognize, acknowledge, and remove these barriers for real progress to be made. (60) To keep up with current Indigenous health issues, Canada needs to actively participate in the process of combining multiple identities, interconnected histories, and a shift in power relations.(62) Furthermore, western research should itself be decentered, (105) which is why implementing a decolonizing framework throughout the data collection and interpretive phases is so essential in this research. Integrating Indigenous peoples and communities within the research project itself creates a healthy starting point from which storylines, collaborative experiences, and overcoming tensions between conventional and traditional knowledge systems can come together to create a better future. (19)

2.2.2 Two-Eyed Seeing

Western and Indigenous science are now converging as equally credible knowledge sources. (42) Many studies focus on two-eyed seeing as a new way to approach Indigenous research. (108–115) Two-eyed seeing is a recent framework introduced by Mi'kmaw Elders Albert and Murdena Marshall from Unama'ki (Cape Breton), Nova Scotia, in the fall of 2004. (108) Two-eyed seeing takes two different knowledge systems, traditional and western, and combines them into one model of understanding. For example, it takes experiential knowledge, such as narratives or lived experiences, from Indigenous ways of knowing and integrates them with aspects of western scientific knowledge, such as data, facts, and information. (80) This approach is important, and appropriate, because Indigenous patients combine aspects of

traditional and western models of care when describing their cancer experiences. (41) Two-eyed seeing, in the context of this study, is better understood as a spectrum between Indigenous traditional ways of healing and western medical practices.

Although Indigenous women are not opposed to western cancer treatments, they do questioned why their cultural beliefs, such as holistic health, should be suppressed throughout the process. (28) Some even describe western treatment techniques as not being 100% effective. (92) For example, some Indigenous patients feel that western machines are not able to detect their cancer when, at times, the cancer may camouflage itself with discolored organ tissues. However, other studies report that traditional viewpoints on cancer perceive it as a white man's disease and therefore can only be cured with white man's medicine. (79,116) Recognizing traditional Indigenous and western beliefs with respect to cancer care has the potential to lead, and guide, Indigenous peoples in developing more appropriate treatment approaches and screening processes, (31) since their choice of treatment may vary so much.

Indigenous peoples should not feel torn between following medical advice, and embracing their cultural understandings of health. For some Indigenous patients, holistic health and spiritual beliefs play a very important role in the decision-making process around cancer treatment (117) In these cases, viewing health through only a biomedical lens diminishes the importance of other factors that can influence a person's level of well-being, (43) and traditional treatment options are then considered essential for healing completely.

2.2.3 Cultural Safety

Cultural safety is based on the critical race theory, which focuses on the principle of biculturalism, wherein the influence of one's social, economic, and political position in society plays a major role in their health status. (58) Many scholars have focused on cultural safety as a

theoretical perspective, as well as a concept when understanding marginalized patients within the healthcare system, especially Indigenous peoples. (118,119) It has been defined as "...shared respect, shared meaning, shared knowledge and experience, of learning together with dignity, and truly listening". (20)^{p.1663} Cultural safety is a concept developed by Maori nurses in New Zealand who saw structural inequities, unequal access to care, and limitations in life choices for Indigenous patients in their healthcare system. (18) There are four parts of cultural safety which are cultural: humility, awareness, sensitivity, and competence. (120)

Cultural humility is a lifelong journey of learning and self-reflection that involves being open to learning about others and listening without judgement; it is the main building block of cultural safety.(120) For example, I spent a lot of time throughout this study getting involved in different Indigenous organized events such as Rock Your Roots, Wicihitowin Aboriginal Engagement Conference, and All Nations Traditional Family & Youth Gathering. Going to these events allowed me to re-evaluate my own understanding of Indigenous culture and gain first-hand knowledge of traditional Indigenous practices.

Cultural awareness is recognizing the differences and similarities that exist between cultures, such as languages histories, and beliefs. (120) For example, it was so enlightening joining in pipe ceremonies, smudging, and sweat lodge ceremonies at Whitecap Dakota Nation. This process helped me see the cultural differences and strengths of traditional Indigenous practices. Healthcare professionals, at all levels, will gain a deeper understanding of traditional Indigenous medicines, practices, and beliefs by engaging with these communities directly. It is very helpful for healthcare providers to become involved in cultural activities within Indigenous communities to build a deeper understanding and relationship with Indigenous peoples. (121) This needs to be integrated better into healthcare professional training, especially for frontline

workers who may not be required to take Native Studies at the university level and are missing out on valuable lessons from Indigenous communities around them.

Cultural sensitivity is acknowledging personal biases and having the courage to admit and reshape them. (120) It is important to note that this is *not* about treating everyone the same; it is about being respectful to other peoples' way of life and cultural backgrounds.(120) To avoid such assumptions, healthcare providers need to be aware of the diversity within Indigenous beliefs, practices, and traditions, so as to not stereotype individuals within the healthcare system. (121) For example, traditional medicines, healing practices, and spiritual beliefs are considered cultural strengths and concepts that need to be further supported in the healthcare system to improve the decision-making process around cancer treatment for Indigenous patients. (28) This is important because some Indigenous women restrict their communication about traditional approaches to cancer care because they fear being judged by medical staff. (28,76) When healthcare providers are more informed about patients' fears and misconceptions about breast cancer, they will be more effective at addressing early detection strategies. (34) Culturally appropriate care for Indigenous patients resonates with the notion of historical or intergenerational trauma, which first addresses having a culturally safe space within the healthcare system. (76)

Cultural competence is an aspect of cultural safety that includes "...a set of congruent behaviours, attitudes, and policies that come together in a system, agency, or among professionals that enable that system, agency, or those professionals to work effectively in cross-cultural situations". (121)^{p.211} In other words, these are skills that we develop over time with knowledge and changing attitudes that work effectively towards respecting the diversity of other people.(120) This does not mean we have to become experts in cultures other than our own;

however, it does mean that we have to reduce the number of assumptions we have towards other peoples.(120) For example, improving healthcare providers' knowledge about patient levels of acculturation and a good communicative exchange on treatment options are essential for improving doctor-patient relationships. (77) Another important step is integrating appropriate materials developed by local Indigenous communities, such as pamphlets, banners, and artwork, allows Indigenous women to have more control over this aspect of their lives. (96) Some effective strategies for promoting breast health for Indigenous women are face-to-face interventions, culturally appropriate educational materials, and using traditional healing methods such as storytelling to enhance holistic healing practices. (35) It has also been found that Indigenous patient comfort levels increase when healthcare organizations respect a patient's cultural beliefs by incorporating traditional medicines, ceremonies, and healers within the patient's treatment plan. (40,76,87)

Chapter 3: Research Methodology

3.1 Introduction to Analysis Process

In this chapter, I discuss my research question, the recruitment process and sampling technique, the data collection process, rigor, ethical considerations, the research design, interview protocol, and the data analysis. An inductive thematic analysis (ITA) was used to identify and code themes found within the data and to compare those findings to recent literature in the field. This is done in order to find similarities and differences so we know what is unique about Indigenous women's experiences with breast cancer in this area. The data was analyzed and coded using a decolonizing methodology meaning that the women's voices were the main knowledge source.

It is important, through a decolonizing methodology, to place the participants in the centre of this work and allow their voices to explain the phenomena. A decolonizing framework encompasses the methodological process. For researchers, it is about having a more critical understanding of the underlying motivations, values, and assumptions that inform research practices. (16) In this study, it is about working with different Indigenous organizations such as the First Nations and Metis Health Care Services and the Saskatoon Tribal Council. It is also about including Indigenous participants, Lorna Arcand, in the development of the interview script and analysis processes. It is also about including Indigenous liaisons, Tanya LaFontaine, to inform the research team on proper cultural protocols and practices when engaging with participants; such as wearing long skirts, giving tobacco as an exchange for their story (which is also a gift), and making sure that the women are not on their moon cycles (menstruating) when listening to their stories or dealing with sacred possessions (like the tobacco offerings). Another part of the decolonizing methodology is that Dr. Groot was present and involved in every part of

the collection and analysis phases, as he is a clinical surgeon who deals with cancer patients regularly and it is so important he is involved in each stage of this research project.

3.2 Research Questions

The following research question and two sub-questions frame this study:

What factors influence Indigenous women with breast cancer from the Canadian Prairie region to make decisions about cancer treatment?

- 1) What roles do culture, social support, community, access to health care, and their relationships with health care providers play in their decision making process?
- 2) What recommendations do these Indigenous women suggest for improvements in support for breast cancer treatment in health care settings?

3.3 Recruitment Process and Community Engagement

Participants were recruited from various geographical locations in Saskatchewan, and Alberta, and Manitoba. Participants were recruited through referral sampling, which is a purposive sampling technique. (122) Dr. Groot initially attended an Aboriginal Health Symposium held in Saskatoon, put on by the Saskatoon Health Region (SHR). At the Symposium, Dr. Groot spoke with Corey Miller, the Vice President of Care Services at the Saskatchewan Cancer Agency. Miller then introduced Dr. Groot to Gabe Lafond, Director of First Nations and Métis Health Services whose office is at St. Paul's Hospital in Saskatoon. Dr. Groot went to meet Lafond and his office staff, and told them about the project he was interested in doing (interviewing Indigenous women with breast cancer to understand how they make decisions around cancer treatment). Lafond suggested Dr. Groot get in contact with some of the Elders from the community so he was directed to Elder Gilbert.

Within this time, Tania Lafontaine was hired as a consultant for the SHR, and assisted our research team in following appropriate cultural protocols when meeting with members of the Indigenous community and connecting us with Lorna Arcand who became the main Community Liaison for this research project. Dr. Groot and Elder Gilbert had a meeting together where Gilbert shared his story with Dr. Groot and Dr. Groot explained the research project he wanted to do. Lafontaine arranged for a few of the members of our research team (Dr. Groot, Chanda Hetzel, Tamara Waldron, and Shelley May-Neufeld) to meet Elder Gilbert at St. Paul's Hospital.

During the meeting, we gave an offering of tobacco to Elder Gilbert to show respect for Indigenous cultural practices wherein a tobacco offering is the first step in building relationships with one another. Tobacco is a sacred herb in Indigenous culture that, when offered as a gift, is used in ceremonial practices to pray to the Creator for guidance in what it is you seek. It establishes a direct connection between the person and the spirit world.(70) In this case, it was to seek guidance in doing a research project taking on a decolonial methodology wherein dominance is neutralized and an attempt at reversing the harm from colonial practices is exercised. After the tobacco offering was given, Elder Gilbert then did a ceremonial prayer in his native language to bless our work and ensure that the project followed through with the participants' best interest in mind.

Later, Dr. Groot met with more Elders in the community including Maria and Walter Linklater, as well as Lorna Arcand, who became a key member of our research team. Arcand is a Cree woman who is a breast cancer survivor. She became the main liaison on our research team because each participant from the project was contacted through Arcand; we could not have done this research without her.

Once Arcand received the participants' permission for an interview, Dr. Groot's research assistant, Shelley May-Neufeld, contacted them directly to arrange a time and place of each interview, as well as sent them a summary of the study so they had a chance to read it over and think about their responses before the interview occurred (See Appendix A). Honoria of \$300 was given to each participant for their participation in the study.

3.4 Participants

This was a qualitative study where one-on-one interviews were conducted with 12 Indigenous women, who have a history of breast cancer and reside in the Canadian Prairie region. The recruitment process was accomplished through referral sampling wherein Lorna Arcand was the Community Liaison who networked with participants to ask if they would be interested in joining the study.

3.5 Data Collection

The study was designed with the intent that the participants were the main educators, or knowledge providers aligning with a decolonizing framework. Each woman decided on the location of the interview, in order to increase their level of comfort when talking about this sensitive subject. The interview process was primarily co-conducted by Dr. Groot and Dr. Roberts. This was very important because it followed a decolonizing framework where medical professionals were present for the interviews, sitting face-to-face with Indigenous patients and building relationships with them. I was also invited to join, but only with the participant's consent. Each woman was also given the interview questions prior to meeting, so they had some time to think about their responses before we met with them (See Appendix B).

Semi-structured interviews were opened through an introduction of both parties, Dr. Groot offered tobacco to the participant, and discussed the research project. An offering of

tobacco allowed us researchers an opportunity to gain insight into the traditional teachings of Indigenous culture, which is a customary practice when approaching an Elder or knowledge keeper.(123) This also aligned with a decolonizing framework where Indigenous ways of knowing were valued and practiced throughout the research process. Dr. Groot described his own experiences as an oncologist having difficulty getting through to his Indigenous patients and wanting to make a change in medical practice so the healthcare system is approaching cancer care in the most culturally appropriate way. Participants were asked about their cancer journeys, how they made decisions around their breast cancer treatments, what worked, what did not work for them, and what they would have liked to see done differently.

3.6 Methodological Rigor

Credibility was achieved by using several pieces of information such as interview transcripts, audio recordings, observations, and field notes. This was done to increase validation on the results found. It also ended up that the women varied in age, ethnic status (First Nations or Métis), and location (SK, AB, MB) which increased the extent of the phenomenon being studied. Data saturation was achieved when no additional information was identified within the interview transcripts by the researchers, or the research team. Themes found within the interviews were then compared to the recent literature in the area to define similarities and differences within this population compared to others across Canada, and the globe. It also helped define the unique needs of Indigenous women in this area when it came to breast cancer decision-making.

3.7 Ethical Considerations

It was absolutely essential to include local expertise, proper reporting back to the communities, and appropriate ownership of information to the participants when doing this research project. This process included many community networks, respecting local knowledge

systems, and having high involvement with Indigenous communities throughout all phases of the research project. (19) This was done to ensure everything was ethically sound and followed a decolonizing framework.

Ethical approval was sought from the University of Saskatchewan and University of Regina Research Ethics Boards on April 25, 2016 (See Appendix C). Approval was also accepted from the Indigenous community through the Council of Elders from the Saskatoon Health Region.

All information regarding consent was addressed during the time of the interview where participants were given a choice of written or oral consent. During this process, participants were asked if an audio recording of the conversation was permissible. Participants were also asked to sign a consent form immediately before the interview began, and given a copy themselves. Two copies of the interview script were visible during the interview (one for the participant, one for the interviewer) and an honorarium of \$300 was given to each participant for their contribution to the project.

The potential risks were covered during this time wherein participants were informed that the interview may evoke feelings of discomfort or uneasiness with telling their story, possibly triggering psychological, mental, or emotional distress. Participants were assured that they were free to stop the interview at any time, and were allowed to refuse any questions they did not want to answer. In addition, we were also prepared to provide referrals for counselling and other services from the First Nations and Métis Health Services at the Saskatoon Health Region.

Patient confidentiality was protected and gone over during the consent process wherein each participant was informed that any information we obtained would be stored on password protected computers. Hard copies of the transcribed interview(s) were mailed to individual

participants, at their request. Data security was ensured by keeping all electronic files on password protected computers and all hard files in a secure place on campus where only members of the research team had access to them. All documentation from this study was kept under password protected computer files for the duration of the study, and will be shredded and deleted 5 years after the study is complete.

3.8 Research Design

This research followed a decolonial methodology that is aimed at better understanding Indigenous health research.(43) Dr. Rose Roberts has summed up this process using a metaphor depicting Canadian and Snow Geese during their migratory trips. The Canadian Geese representing Indigenous peoples and the Snow Geese representing non-Indigenous peoples. They both need each other to migrate, just like we as people (from different cultural backgrounds) need each other to do this research. At the end of the day, both groups eventually go their separate ways; however it is the journey that they take together that is important - for we could not accomplish our intended goals without working with one another. This can also be described as a process wherein one group is not superior to the other; one does not walk in front or behind the other but instead we walk beside each other throughout this journey of understanding.

Because this methodology looked at two different ways of viewing the world, a theoretical lens of two-eyed seeing was used during the data collection and analysis phases. Two-eyed seeing is a term coined by Indigenous Mi'kmaw Elders Albert and Murdena Marshall as a way to bridge western science and Indigenous knowledge together. (108,110) To follow this mandate, Dr Groot intentionally chose members of the research team who came from various (Indigenous, non-Indigenous, and multi-disciplined) backgrounds.

3.9 Interview Protocol

Twelve Indigenous women participated in the study in open-ended, semi-structured interviews allowing them to tell their story with breast cancer and how they came to their decisions around treatment choices. The interviews lasted up to two hours each and took place between May 2016 and January 2017. The participants chose the interviewing location, keeping in mind that a quiet location was best to record our conversation for transcribing purposes. Participants were able to invite members of their family, or community, to join in the interviewing process if they chose to do so. They were also invited to stop the interview at any time that they felt uncomfortable or wished to stop.

Once participants agreed and signed the consent forms, recording devices were turned on and the interviews began. The interview was designed in an open-ended format so participants were encouraged to tell their own story with breast cancer rather than answer fixed questions. With the participants' consent, all interviews were audio recorded on digital recording devices and transcribed at the Social Science Research Laboratories (SSRL), at the University of Saskatchewan.

3.10 Data Analysis Strategy

The transcripts were interpreted using inductive thematic analysis (ITA) which is an iterative way of collecting and analyzing data meaning that themes found within the data set were verified by looking at similar literature related to Indigenous women with breast cancer. The data analysis process was conducted in a 6-step process; 1) familiarizing yourself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing the themes, 5) defining the themes, 6) producing a report. (124) Thematic analysis was suitable for this study since I was trying to understand what is unique about Indigenous women's experiences making decisions around breast cancer treatment. Taking an ITA approach in this study highlighted some of the

deeper issues Indigenous women face when making some of those decisions. A thematic analysis can be done in many ways and I chose to do my thematic analysis as a rich description of the data set, through an inductive process, focusing on latent themes, and using a constructionist epistemology.

By analyzing a rich description of the data set, this allowed me to find themes within the transcribed interviews that spanned across the entire data set. Themes are meant to capture something important about the data in relation to the research question and are typically structured as a patterned response within the data. (124) This gave me a richer description of the overall picture surrounding breast cancer decision-making from the participants' perspective. This means that themes that were similar for most, or all, of the participants were defined as main themes, instead of focusing on themes found from one or a few participants alone. This was an iterative process where themes were identified by comparing information gathered from all the interviews.

An inductive approach to thematic analysis means that the themes that were found from the study were strongly linked to the data itself. (124) This also implies that there cannot be a pre-existing coding framework since the analysis was data driven. This means that the participants' one-on-one interviews were the main source of information from which the findings were focused on. Although some depth and complexity may be lost during the analysis, this approach was particularly useful when investigating an under-researched area, or working with participants whose views on the topic are not known. (124) Because there was so little research out there focusing on the decision-making process that Indigenous women experience when going through breast cancer treatment, a rich inductive thematic analysis was ideal for this study.

Latent themes are themes that focused on deeper interpretations of the words spoken. In this respect, a two-eyed seeing lens was used to interpret the main themes.

The actual interpretation of the interviews took place in a six step process as defined by Virginia Braun & Victoria Clarke in their work, *Using Thematic Analysis in Psychology*.(124) The six steps will involve: 1) familiarizing yourself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing the themes, 5) defining and naming the themes, and 6) producing a written report of the results. (124) Each step played an integral role as to accurately reflect the overall themes that were found across the data set within the study.

Familiarizing yourself with the data is the first step which is reading over the transcribed interviews a few times and jotting down your initial thoughts. The second step is generating initial codes which are any and all themes pulled out of the entire data set to begin a systematically organized structure. The third step is searching for themes meaning you are collating your potential themes into categories. The fourth step is reviewing the themes chosen by looking at the initial ideas found in the first step and comparing them to the entire data set (those found in the second step) and creating a thematic map with that information. The fifth step is defining and naming the themes which are on ongoing analytical process wherein you synthesize the findings into one whole story and define each theme by name. The sixth and final step is then producing a report that accurately reflects the overall themes in the data by selecting specific examples in that data that relate to the original research question and literature around the topic.

3.10.1 Phase I: Familiarity

The first phase of the analytic process is to listen to the audio recordings, while reading through the transcriptions, and jotting down any initial thoughts about each interview. Since the

transcriptions were not completed by me, I listened to the audio recordings of the interviews and comparing it to the transcription to ensure that the written text accurately reflected the verbal accounts of the participants. This means that any grammatical errors found in the transcriptions were corrected in this phase. I also jotted down my initial reactions, in a word document file, after first hearing them.

3.10.2 Phase II: Initial Coding

This phase included coding any of the semantic (surface meaning) data that was interesting in the transcriptions. This was accomplished through a data-driven critique of the interviews meaning that the themes were identified from the data (interviews) themselves. This was done by importing all of the word document transcriptions into the NVivo11 Software Program which allowed me to start coding extracts of information from the data set. During this phase, I conducted three main tasks. First, I highlighted all of the potential codes/themes from within the data set that I found interesting and directly related to my research question. Second, I was inclusive when highlighting text extracts so I did not lose important information around a certain topic. Third, I kept in mind that information I highlighted was not coded in a mutually exclusive manner meaning that one extract could be coded into multiple different themes. It was also very important to document any accounts that veered from the dominant story. It has been suggested by Smith & Osborn that an idiosyncratic approach during this stage in the analysis is important wherein the researcher should look at one interview, in detail, one at a time, case-by-case. (125) This way I was able to start with more specific examples and slowly work up to more general categories.

3.10.3 Phase III: Theme Searching

In this phase, a finer focus of the themes took place wherein coded extracts are collated into broader, overarching themes. At this time, I looked at the codes I identified and categorized them into larger themes, and constructed a mind-map to have a visual depiction of the relevant themes identified thus far.

Initial codes became main themes, subthemes, or discarded during this phase. Some other themes that did not fit in with any of the main themes identified were placed in a miscellaneous folder temporarily. Significant themes became apparent and it was important not to completely get rid of any information, at this point.

3.10.4 Phase IV: Theme Review

During this phase, patterns in the coding were identified. I went through the themes created to determine if they were prevalent enough in the data set to remain a theme. Prevalence was measured by the number of times a different speaker articulated the theme across the entire data set; and how many speakers spoke about that particular theme. Themes, at this stage, become separated, compiled, or eliminated altogether.

This phase occurred in two stages. First, I re-read all the collated extracts and decided if they created a pattern. If the themes did not fit, then they were re-worked as an existing theme, a new theme, or discarded from the analysis. Then, a thematic map was made of that data. The second stage was to do that again but across the entire data set determining if the map accurately reflected the whole data set.

Once the process of re-coding led to a more nuanced coding framework, I stopped. After this phase was complete, the main themes were clear, patterns fit well together, and I was able to tell a story about the data set.

3.10.5 Phase V: Theme Definition

This phase was when I defined and redefined the main themes I identified. In this phase, I went over the core of each theme and determined which part of the data it captured. I then wrote a detailed description of each theme as well as a story to go along with them. After, I had to determine if I had identified my themes well enough by testing one to see if I could describe each theme (and its scope) in a couple sentences. If I could not, further refinement was made so the main themes stuck out and were attractive for the reader to grasp.

3.10.6 Phase VI: Report Production

This phase was when a final report of the analysis is made. At this point, I wrote up a report on the main themes I identified. The themes were prevalent enough within the data set that enough extracts could be used to demonstrate each theme sufficiently. I wrote my results in a structured thematic form, so the results made sense and the relationship between the themes and the research question were easily understood and intimately connected.

Table 3. 1: Example of Theme Development

Original Transcript	Phase I: Familiarity	Phase II: Initial Coding	Phase III: Theme Searching	Phase IV: Theme Review	Phase V: Theme Definition	Phase VI: Report Production
<p><i>I've got to work. I've got to feed my kids. I've got to pay my bills</i></p>	<p>Difficulty with personal financial responsibilities after breast cancer diagnosis</p>	<p>Concerns about her job, concerns about feeding her children</p>	<p>Barriers around making a treatment decision</p>	<p>Socio-economic status</p>	<p>Socio-economic status was a barrier that had anything to do with the individual's financial situation that was out of their own control – eg. everyday responsibilities, poverty, and medical expenses.</p>	<p>Socioeconomic status was mentioned 40 times by 8 participants, and was either a barrier or impacted their decision-making process around breast cancer treatment.</p>

3.11 Summary

I chose to use an inductive thematic analysis (ITA) because information on this type of study - understanding the decision-making process of Indigenous women with breast cancer while going through cancer treatment - is largely unknown. Also, other members of the research team did other types of analyses. For example, Rose Roberts did a narrative inquiry analysis of the interviews. Taking a decolonizing approach ensured the women were the main voices of this study, wherein their stories created a sense of agency and most accurately depicted their decision-making process about breast cancer treatment. They were also shown to the participants and the Saskatoon Tribal Council to establish methodological rigor.

When trying to understand diverse perspectives in qualitative data, thematic analysis allows the researcher to discover information through interpretation by providing a systematic approach to how themes are identified. (126) A theme is, "...a specific pattern of meaning found in the data". (127)^{p.209} Themes describe patterns of implicit and explicit content. (127) Furthermore, the emphasis of a theme is not dependent on quantifiable measures but whether it captures something significant in relation to the research question. (124) According to Victoria Braun and Clarke, "Thematic analysis is a method for identifying, analysing [*sic*] and reporting patterns (themes) within data". (124)^{p.79} The importance of thematic analysis is that it shifts measurement to understanding; causation to meaning, and statistical analysis to interpretation. (127) Thematic analysis provides a useful research tool that is flexible and can provide a rich, detailed, and complex account of the data collected. (124)

The method of analysis was inductive meaning that it derived from the raw data itself. (127) It was also important to reflect back on the literature related to the topic to make sure it aligned with similar findings; (124) however; it was crucial to remain open to new concepts that

emerged that were unique to the study. (127) It was an iterative process of coding, writing, theorizing, and reading that takes place simultaneously. (128) This means that the analysis was driven by inductive codes of the raw data, and theoretical codes derived from past literature written in the area. (127) Because the analysis was an iterative process there was an interplay among the procedure of data collection, literature review, and research reflection. (128) The importance of a literature review in truth-telling has the ability to go beyond healthcare interactions where sensitivity and subtle nuances in the data could be enhanced. (128) For example, in the final write-up section of the thesis phase I was able to more accurately confirm my findings by going back to the literature after the analysis was completed; allowing me to challenge and add to that literature. (128)

Thematic analysis is important when studying group phenomenon in order to establish valid models of human behaviour, thinking, and feeling. (127) Thematic analysis actually derived from content analysis which exclusively focuses on the frequency outcomes generated. (127) Thematic analysis allows the researcher to add value to the themes found; adding meaning to the subtlety and complexity of the phenomena under study. (127) It often draws on the social constructionist theory which does not focus on individual psychologies, but instead on the structural conditions and sociocultural contexts that enable individual accounts of the situation, (124) which is what I wanted to accomplish coming from a sociological perspective.

Although the methodological procedure is presented as a linear, step-by-step process, the analysis was a reflexive and iterative process. (124,129) The reason thematic analysis is systematic and transparent during the analysis is because this allowed other researchers to track the process and, if necessary, change them. (127) It also allowed for rigor to take place ensuring

that interpretations made from the data were connected to the research question drawn directly from the subject matter, rather than made through assumptions. (124)

NVivo 11 Pro was the computer software program I used as a tool to help me code themes found in the transcriptions. There are many reasons that computer programs such as NVivo are important in analyzing qualitative data such as: it allows the researcher to deal with more interviews than can be done manually, it can handle large data sets finding comparisons between groups, it assists the researcher in looking at coding patterns, it creates links between codes, sequencing and co-occurrence can happen in a highly systematic fashion, and the retrieval of data is far easier. (127)

Thematic analysis fits in with a decolonizing framework because it focuses on the participants' social reality rather than replacing it with a fictional reality that is constructed by the researcher. (127) Qualitative research involves a series of questions that needs to be analyzed clearly to build a relationship between the various interview questions with the overall research question. (124) For example, this project focused on how Indigenous women make decisions around breast cancer treatment wherein the interview process was open ended and semi-structured with questions that allowed the women to talk about their upbringing, family history, and their personal social roles that directly connected to how they made decisions around breast cancer treatment.

Chapter 4: The Women

4.1 Introduction of the Women

As an introduction to the women, I mention each using a pseudonym then describe their cancer diagnoses and individual identities as well as their treatment choice, main concerns, and the outcome their cancer experience had on them. Ten of the women identified as First Nations and two as Métis. Four of the women said they were Christian and used their spiritual faith as a support throughout their cancer experiences. Almost all the women (except two) said they used their Indigenous spirituality to get them through their cancer journeys. Eight of the women used traditional medicines from Indigenous healers or Elders. Six of the women had a mastectomy, and of those six, three had reconstructive surgery and three had prosthesis. Five of the women had a lumpectomy, and four had a hysterectomy (either prior, during or before their breast cancer treatments). Three women also had lymph nodes removed. Six of the women had chemotherapy, and seven had radiation. Six took Tamoxifen. Four of the women received some or part of their treatment outside of the province. Seven of the women were diagnosed with breast cancer at a young age (under the age of forty years old), one woman was diagnosed in her late forties, and two of the women were diagnosed in their sixties. Everyone mentioned their family as being a main source of support, and six mentioned that their husbands were a major support for them. All of the women found their breast cancer themselves, two regularly went for mammograms but the machine did not detect their cancer. Two of the women waited four years between finding a lump and getting diagnosed, one went for a year, and the rest were diagnosed within a year. Most women mentioned concerns about having additional emotional support, especially right after the diagnosis, so there is not so much fear of the disease and having someone to talk to about what

steps they should take, or at least someone they could relate to while going through their cancer treatments (knowing what to expect).

4.1.1 Stacey

Stacey is from North Battleford and had most of her treatments at the Saskatoon Cancer Centre. She was 37 years old when she first realized something was wrong with her when she felt a soreness in her chest and started eating a lot of sugary foods because she was constantly fatigued. Four years after this she went to the doctor to get checked out. The first doctor told her it was just a fat gland but her and her husband were not satisfied with the prognosis so got a second opinion; about two months later she found out she had breast cancer. Stacey chose to get chemotherapy, a double mastectomy, and radiation after her surgery.

Stacey also chose to take traditional medicines by drinking teas given to her by an Indigenous healer during her chemotherapy treatments. She never told her oncologist about the medicinal teas however her chemotherapy plan went from eight treatments down to six because of the decreasing size of her tumor at that time. Stacey also decided to get the reconstructive surgery despite her husband and family's disagreement with that decision. One of her co-workers felt that she had pressured Stacey into getting the reconstructive surgery; however Stacey assured her, and herself, before the procedure that it was ultimately her choice to go through with it.

Stacey's main support was her husband and she felt that the hardest part of her cancer journey was having to tell her children about her diagnosis. Stacey suggested that the physicians at the healthcare facilities be the ones to initiate conversations about culture and belief systems so that Indigenous patients, such as herself, would feel more comfortable sharing their way of healing, such as drinking teas, while going through their cancer treatments.

Stacey used her faith as a First Nations woman, as well as her Catholic beliefs, to give her spiritual strength throughout her cancer journey. Stacey portrayed a high level of self-efficacy where she spoke up for herself and made her own decisions with the love and support of her friends and family (even if they did not always agree with her decisions). Now Stacey shares the importance of helping other Indigenous women and their cancer journeys, stressing the importance of listening to your body - do not ignore it!

4.1.2 Quintan

Quintan is from the Edmonton area and received her initial treatments at the Elbow River Healing Lodge. Quintan identifies as a Métis woman with a Roman Catholic background; however when she was a young adult she became more connected to her Indigenous roots. Quintan married an Indigenous man and had a traditional ceremony where they swore on eagle feathers. Her husband left her shortly after for another woman and Quintan, to this day, still considers herself a married woman because she took that ceremony and her traditional culture very seriously.

Quintan frequently went to Indigenous ceremonies and in 2011 had a healer tell her she had a dark spot on her chest. She initially thought it was her broken heart and did not think too much into it at the moment. Two years after that, in 2013, she felt what she describes as a rock in her breast while sleeping on the couch. In 2015, when she was 64 years old, she went to the doctor to get a mammogram and MRI. The first doctor she was referred to asked her if she fell which she thought was outrageous given the situation she was in (at the cancer centre getting checked for breast cancer). She decided that doctor did not know anything and got a second opinion shortly after to discover that she did have breast cancer.

Quintan had chemotherapy treatments and some of her lymph nodes removed (which she described as an offering to the Creator). She decided to get a lumpectomy because that is what the doctor suggested and she is in the process of moving into her radiation treatments. Quintan did a lot of smudging during her chemotherapy treatments to help with the healing process. Quintan's main support was from her daughter and her spiritual beliefs, as well as staying busy with work which is working with residential school survivors and is very fulfilling for her.

Quintan displayed a high level of self-efficacy and kept a journal of all the things her body was going through during her chemo treatments. Quintan's main concerns were with the lack of consistency within the healthcare system where she felt that she constantly had to explain to each practitioner that she was not comfortable with a male doctor touching her breasts, which were important to her from her strong cultural beliefs.

She also had difficulty during her cancer treatments with a latent form of tuberculosis(TB) that she had since she was young. She received treatment for her TB while going through cancer treatment at 64 years old which she thought was a failure on the communication between the healthcare system and its patients. She described how she gets a letter in the mail every year for pap smears (which she has no interest in) but never received any information about this TB treatment that she would have very much liked to get as soon as it was available.

She made an important point about how the healthcare system is reactionary instead of preventative (which was a statement she expressed to one of her healthcare providers). Quintan is still going through her cancer treatments and hopes that in the future it will be easier for patients to have consistency with their physicians so they are able to build trusting relationships with one another.

4.1.3 Erika

Erika is from Saskatchewan originally but was in Ottawa during her initial cancer treatments, then Switzerland, and now lives in Guatemala. She received her cancer diagnosis at the Ottawa Regional Centre which she described as a great facility. Erika and her two sisters (Gina and Tara who are also a part of this study) were all diagnosed with breast cancer within the same year (1999). Erika was under 40 years old when she received the news and found it very difficult to find a support group geared towards younger women with breast cancer.

Erika decided to get chemotherapy, then a lumpectomy (which she said she would have chosen mastectomy if she had the choice now, just because of her family's history with cancer). She then did radiation and brachytherapy. Because she was away from home during her cancer diagnosis, she largely depended on a friend she made in Ottawa as well as her doctors for a strong support system. She also found guidance and support through *Dr. Susan Love's Breast Book* which has been described as the bible for the newly diagnosed.

Erika does not consider herself a spiritual person so did not find any cultural belief system to be of value to her during her cancer experience. However, she did express difficulty in finding other Indigenous women to relate to and especially women who were of the same age as her. Because she was diagnosed so early in her life and was being told about 5-year and 20-year survival statistics, she took a more fatalistic approach to life after her diagnosis. Today she continues to get annual mammograms and works abroad for the Canadian Embassy in Guatemala.

4.1.4 Gina

Gina is Erika's sister and was diagnosed in the same year (1999) at 39 years old. She received her treatment at the Cross Cancer Centre in Edmonton. Shortly after she visited her

sister Erika in Switzerland, she felt a lump on her breast. She waited a couple months to get diagnosed because she thought it would "go away" however she says now that she was probably in denial of it at the time.

Gina decided to get chemotherapy and a lumpectomy. While she was at the healthcare centre they also gave her an ultrasound on her abdominals and found something there. She went for surgery quickly after and they informed her that if it was cancerous that they would remove her ovaries in the OR. She begged them to keep one ovary so she would not go into early menopause. After she woke up six hours later she knew it was cancer and she was grateful that her doctor caught it early on, for it was right at the ovary and had not spread.

In 2011, she found out through a friend that she should be going to the high-risk cancer facility to continue going for follow up appointments. She was not aware such a place existed and when she went in her old surgeon was still there and found another lump on her other breast. She decided to do the prophylactic double mastectomy as her surgeon suggested, at that time. She said during the treatments she was on Cisplatin and 5FU and Doxorubicin. After her treatments she lost about 40 pounds and became more healthy in her lifestyle choices (diet and exercise).

Gina had a strong support system especially from her Catholic church community, as well as her parents and family. Her main concerns were that there was no follow up with her case, especially with being a high-risk patient and having the genetic mutation. She strongly supports the nurse navigators and has clarified that she herself is a healthcare professional, a pharmacist, so she was able to understand the terminology better than most people would.

She knows that she has high self-efficacy due to her upbringing in an urban centre and her knowledge as a pharmacist but she is worried about Indigenous peoples who live in rural

areas, such as in the Northern regions, and may not be able to speak up for themselves to the same degree that she was able to.

4.1.5 Tara

Tara is the other sister of Erika and Gina, diagnosed in the same year (1999) at 36 years old. She identifies as First Nations and did some of her treatments in Regina and some at the Saskatoon Cancer Clinic. Tara found the lump herself when she was at a funeral and put her hand up to her chest and felt a thickening. When she went to the doctor to get diagnosed, the doctor told her he was 99% sure it was not cancer. She felt like he did not understand her and her family's history with cancer, as well as the increased chance of the genetic mutation.

Tara knew it was cancer the moment she felt it and luckily went in right away and caught it in stage one. Tara decided to do the mastectomy and radiation. She also had two reconstructive surgeries because the first one was a saline implant which collapsed. The second reconstructive surgery she had silicone implants put in and was expecting to have 'Pamela Anderson-like breasts' but woke up to being very disappointed with the surgery, calling herself Frankenstein. She felt as though her Indigenous status made her less important in the healthcare system (as her last name is very Indigenous sounding and may have caused the staff to stigmatize her because of it). She noted how advanced technology is today; however her experience with it [the reconstructive surgery] was so disheartening and she truly felt that her identity as an Indigenous woman was the main reason she did not receive the same level of care as others.

Tara received a lot of support from her husband and family; she even had a good-bye party for her breasts to celebrate the purpose they served with her raising and nursing four children with them. Tara was very moved by her cancer experience and made a documentary

about her journey. She had a very difficult time at first because she was going to university and raising four children as a single mother.

She tried to go to support groups but could not relate to the other women there who would talk about going on one last trip to Hawaii as a family. Tara felt worse after going to those support groups because it made her realize how little she had compared these older Caucasian women. In the support group, they also encouraged her to eat lots of fresh foods which was difficult for her when she was just concerned about making a package of hamburger last a week for her and her children; and any fresh food she did have, she gave to them.

Tara described stayed strong for her children by often crying in the evenings in the tub so her children would not see her in that state. She even said that after her diagnosis her first thought was how she needed to get herself together because she was seeing her daughter right after that appointment. She still finds it hard to look at herself in the mirror because she does not find herself as attractive anymore. Tara also liked to sleep on her stomach which is almost impossible to do now with her breast implants. Tara's documentary gave her hope in sharing her journey with other Indigenous women who may be diagnosed as well. She found the process of making the film to be a healing journey in itself and continues to be a strong promoter of breast cancer awareness for Indigenous peoples.

4.1.6 Norma

Norma identifies as a Neheyo Eskwew Cree woman. She is from the James Smith Reserve and received her cancer treatments at the Saskatoon Cancer Clinic. Norma noticed changes in her breast (a puckering) in 2011 when she was only 35 years old. She wanted to have a double mastectomy because her friend suggested she get it. When she told her surgeon that is what she wanted her surgeon said no, and so she only had a mastectomy on the one breast.

Norma follows a traditional path of healing and describes that as her main treatment option. Norma goes to sweat lodge ceremonies, smudges, and drinks teas such as chaga. Norma did not want to go through chemotherapy or radiation treatments so her doctor prescribed her medicine in pill form instead. Now, she takes 14 pills a day to treat her breast cancer as well. Norma also decided against the reconstructive surgery and instead got a prosthesis.

Norma's main concerns with her experience were the lack of accessibility (even in Saskatchewan) for prosthesis clothing like bras and bathing suits, as well as the lack of funding provided to her due to some medical costs not being considered 'proper' medical expenses. Her and her husband even drove to Phoenix, AZ where she was able to find more suiting prosthesis resources for herself.

She wishes that more resources were available in the province, and that those things were covered under some kind of healthcare. She stated that none of her prosthesis clothing was covered through Indian Affairs. She also expressed her concerns for those Indigenous patients who go into healthcare settings and are not from urban areas and/or do not speak English.

She would prefer to have an Indigenous advisor available at the healthcare clinics, especially ones who can translate between patients and physicians. Her main support was her husband who came to all of her appointments with her and drove her to get the appropriate clothing for her prosthesis. She also mentions that she was raised Anglican but found more spiritual support in traditional Indigenous practices. Today she finds it is important to share her cancer journey with others so she can help more Indigenous peoples who are diagnosed with breast cancer.

4.1.7 Laura

Laura is a Cote First Nations from Kamsack and received her treatments at the Saskatoon Cancer Clinic. Laura was 43 years old when she found a lump on her breast, and two months later she was diagnosed. She decided to do chemotherapy and when the doctors kept suggesting surgery, she said no. After her chemotherapy, she took Tamoxifen for 15 years which is normally only supposed to be taken for five.

After all that time, she went back to the doctor who told her her cancer was now aggressive and strongly suggested removing it. She finally decided to, but only because it was aggressive and she wanted to be strong/there for her children. She got a lumpectomy as her cancer treatment choice.

Laura's brother is a well-known healer so she also followed a traditional pathway in her healing journey. She drank teas that he gave her and she consulted with him throughout her entire cancer experience. She did not have many concerns about her cancer treatments because when she told her oncologist she did not want surgery, he respected her decision. She also received support from her traditional way of life and seemed to use both worlds (western and traditional) in the best way that was helpful for her.

4.1.8 Mary

Mary works in High Level, Alberta and identifies as a Métis woman. Mary found her cancer in June 2013 and received her diagnosis in August of that same year. She decided to get a mastectomy and radiation as her treatment options and saw going out onto the land as a healing process for her from her traditional way of life. She also takes Tamoxifen now as another treatment choice.

She had a very good relationship with her healthcare providers and unfortunately ended up breaking her leg during her cancer treatments. Because of this injury, her cancer experience was especially hard and she expressed feeling quite depressed during this time, so she also took anti-depressants to help cope with that.

Her main supports were from her husband and family. She expressed the importance of the healthcare system providing a place for people to stay who are travelling from far away, such as those from the Northern regions, and the need to have family to be there with them (in Saskatoon) during their treatments.

4.1.9 Theresa

Theresa identifies as Saulteaux and was raised as a Christian. She went to residential school for two years when she was a young girl. She is now living La Ronge but she had her biopsy done in Prince Albert, and her main cancer treatments at the Saskatoon Cancer Clinic. She initially found the lump while she was in the shower and booked a doctor's appointment immediately after.

She was 62 when she was diagnosed with breast cancer and decided to do chemotherapy, a mastectomy, and then radiation. She also chose to use traditional medicines, like teas, during her cancer treatments. She discussed her traditional medicines with her oncologist and he encouraged her to keep using them along with her western cancer treatments. She put a lot of trust into her doctors by stating, "You're a doctor, just do what you're able to do with my body."

She had a lot of support from her daughter and her son, as well as her husband who would go out into the bush with her and hunt wild game. She finds it difficult now to still be out on the land because she has trouble with her balance since her cancer treatments. Because of this,

she is afraid of falling over or tripping over something out in the bush and not being able to get back up.

Due to her cancer experience, she totally changed her diet and is a lot healthier now by mostly eating white meats (chicken, fish, turkey), and wild game. She expressed more enjoyment with cooking and has even switched to sweetening her coffee with coconut oil rather than sugar.

Her main concern with her cancer experience was the lack of accessibility to a healthcare facility that was closer to her home. The travelling was really hard on her especially right after her radiation treatments. She also felt there should be more emotional support immediately after diagnosis.

4.1.10 Ruth

Ruth is from Bow River and now lives in La Ronge. She received most of her cancer treatments at the Saskatoon Cancer Clinic. She mistook a soreness in her breasts in 2000 as bruising from the children she worked with because she was a teacher and thought it was from them being rough with her.

The first doctor she went to agreed with her and said it was from the roughness of the children hitting her breasts. One year later she had yellow fluid mixed with blood leaking from her breasts so she went to the minor emergency clinic in Prince Albert where the doctor immediately took her for tests. After she was diagnosed with breast cancer she decided to get a mastectomy. She was unaware of breast reconstructive surgery as even being an option and was told to use a prosthesis from now on to make her 'feel better'.

Mary also decided to use traditional medicines like teas and going to sweat lodge ceremonies. Her main support was her late husband, and late mother, but since they passed

during her cancer experience she also relied on her eldest daughter, and Elders within the community.

Her main concerns were the lack of emotional support she received after her diagnosis and the poor accessibility to the Pink Tree which is a clothing store that caters to women who have lost their breast(s) to cancer and is located in Saskatoon. She would have liked more support available to her in La Ronge so she would not have to travel so far to get the help she needed.

4.1.11 Danika

Danika initially received her cancer treatment in La Pas, Manitoba but later moved to Saskatchewan and went to Saskatoon for her medical treatments. She identifies as First Nations but found support by randomly talking to other women at the clinic while she was there. She found the lump herself when she was 48 years old and got diagnosed soon after that. She regularly went for her mammogram check-ups but the machine did not catch her cancer.

She decided to get a mastectomy and radiation, and chose not to get reconstructive surgery; she chose to get a prosthesis instead. She also used traditional medicines like sweetgrass and smudging to help her through her cancer experience. Her main support was a Persian lady who she randomly met at the clinic one day.

Her main concern was that no one talked about cancer in the Indigenous community and there was a large gap in knowledge there. She believes that most people do not talk about it or do self-breast exams due to the influences of the Indian residential schools (which she experienced herself) where teachings from the church deter people from 'touching themselves.' She would like to push for more supports in her community for Indigenous peoples to learn more about cancer prevention and awareness.

4.1.12 Carol

Carol had her treatments in Edmonton at a medical centre called Healing Connections. She identifies as First Nations and is also a widow. Carol was quite persistent in having online support groups which was her main source of emotional support. She found that talking to women online with similar diagnoses was beneficial in her cancer experience. She was 55 when she was diagnosed with breast cancer shortly after she found the lump herself.

All of her treatments were described to her by her nurse navigator, which she liked. However, she still felt 'in the dark' with regards to having emotional support provided to her. She decided to get a lumpectomy which took place on September 7, 2016, and October 14th was the resection. She was also scheduled to have chemotherapy treatments a month later because the cancer spread to three-four of her lymph nodes. However, she was called into the clinic a week earlier and told that her chemotherapy treatments had been cancelled. This was because her cancer had metastasized which she sort of knew already because of the excruciating pain she was experiencing at the time. After, her physician gave her some cancer and anti-inflammatory medication to treat the disease and help with the pain.

She had become so depressed from the whole situation she actually was planning on scheduling assisted suicide. She decided against this option when she saw the look on her son's face when she was arranging the process. She found that using natural treatments such as cannabis oil and turmeric helped her cope with some of the side effects of the western treatments. For example, the cannabis oil helped alleviate some of the nausea and digestion problems she was having as a side effect from her cancer medications (Letrozole and Xgeva).

Her main supports were her family, friends, God, her psychiatrist, and herself. She found

that being mindful of her thoughts and journaling were very important processes for her during her cancer experience.

Her main concerns were for Elders in her community (some of whom were her peers) who did not have the same level of education that she did. She felt that the healthcare system was not very good at explaining things in laymen's terms which she felt was very important for patients who are not highly educated. She would like to push for more online support, particularly support groups that educate people about their specific breast cancer type, as well as being a platform to provide emotional support, especially for those women who are single or widowed.

4.2 Summary

Table 4. 1: Overview of Participants

#	Pseudonym	Age	Location	Identity	IV Length	Diagnosis	Marital Status	Other therapies
01	Stacey	45	North Battleford	FN	1:23	Breast cancer/reconstruction	Married	Medicinal teas
02	Quintan	65	Edmonton area	Métis	1:09	Breast cancer/undergoing treatment	Divorced	Smudging
03	Erika	<40	Guatemala	FN	0:25	Breast cancer	Single	Not 'spiritual'
04	Gina	56	Edmonton	FN	0:25	Breast and ovarian	Single	No mention
05	Tara	53	Regina/Saskatoon	FN	1:35	Breast/reconstruction	Married	Made film-documentary
06	Norma	62	James Smith	FN	0:35	Breast	Married	traditional practices
07	Laura		Saskatoon	FN	0:45	Breast	Single	Teas (brother a healer)
08	Mary		La Ronge	FN	0:16	Breast/reconstruction	Married	Connection to the land
09	Theresa	65	La Ronge	Métis	0:57	Breast	Married	Teas
10	Ruth	67	La Ronge	FN	0:52	Breast	Widowed	herb drink from 3 healers
11	Danika	56	La Ronge	FN	1:08	Breast	Married	Sweet grass/smudging/prayer
12	Carol	56	Edmonton	FN	0:51	Breast	Widowed	Cannabis oil, journaling, turmeric

Chapter 5: Findings and Discussion

5.1 Introduction of the Main Themes

In this chapter, I summarize the four main themes of: socioeconomic status, access to healthcare services, relationship with their defined culture, and cultural safety or feelings of support in healthcare settings. These were informed by the main research question of: what factors influence Indigenous women with breast cancer from the Canadian Prairie region to make decisions about cancer treatment?

Socioeconomic status discusses how income influenced their decision making process.

This includes:

- everyday responsibilities,
- irrelevant supports for women in poverty, and
- post-surgical accessory support.

Accessibility to health care services plays a role in their decision making process. The women discuss these main aspects influencing their access to care:

- knowledge about the disease,
- location in relation to a health care centre, and
- difficulties travelling for medical services.

The relationship the women have to their culture shaped the women's decision making process. The women identify:

- diverse perspectives of cancer (western/traditional/both), and
- stigmas around the disease influence their cancer treatment decisions.

Cultural safety, or feelings of support in health care settings, assists the decision making process. The women discuss these main aspects when being treated in health care facilities:

- experiences with Indian Residential Schools,
- feeling like a stranger in the health care setting,
- communication differences,
- lack of quality time,
- connecting as a source of empowerment, and
- level of self-efficacy.

5.1.1 Theme 1: Introduction to Socioeconomic Status

"I've got to work. I've got to feed my kids. I've got to pay my bills." - Stacey

I began with the theme of socioeconomic status, which encompassed more practical aspects of the decision-making process and included things such as money, resources, and materials needed during cancer treatments. This was a primary theme; when the women described their thoughts shortly after receiving a cancer diagnosis, they were typically in relation to monetary issues, e.g., "How am I going to pay for this?", rather than their actual health status, e.g., "Am I even going to survive this?". I found this a bit alarming, because the women's primary concern was whether or not they could afford to have cancer and not the disease itself, getting better, or even getting the proper treatment. The three subthemes related to socioeconomic status in the decision-making process around cancer treatment were everyday responsibilities, poverty, and medical expenses.

5.1.1.1 Everyday Responsibilities

"I was so upset [after my diagnosis] and I said [to my husband], "What am I going to do? How am I going to help pay the bills?" We just bought a new house and both of us work and we're able to make payments. We were also looking after our three of my grandchildren – all boys – and they were a handful." - Ruth

A common response amongst the women after their initial diagnosis was ‘how can I afford this?’ The women described having many other responsibilities they needed to take care of, and these were at the forefront of their minds when first hearing about their diagnosis. They either had vehicle payments to make, children or grandchildren to take care of, or felt very uneasy about taking time off work for fear of job loss or just general loss of income.

5.1.1.2 Irrelevant Supports for Women in Poverty

"Poverty sucks and you know I just couldn't see them [in the support group] thinking, "I have one package of hamburger and a week to go. I'm going to have to try and stretch this," so, there was a lot of feeling sorry for myself going on too, right? On top of all that, there's a lot of shame associated with that as well like I have a lot of pride and I thought I have a family that could've helped me but it was my pride that stopped me. It's like, no - these are your kids, your family - you just take care of yourself... I did not want to be on welfare [either], I did not – and you know it was like – I cannot be on welfare." - Tara

Living with a low income was an additional stress the women had to deal with when deciding about treatment options. Poverty impacted their relationships with others, specifically in breast cancer support groups where the other women battling cancer were more likely to be Caucasian and less likely to understand the daily realities that Indigenous women faced, such as being unable to afford healthy food for themselves and their children. We know that within Canada Indigenous women are more likely to live in poverty compared to non-Indigenous women and Indigenous men. (130) As Tara mentions, she felt that her experiences with poverty was something that other non-Indigenous breast cancer survivors could not relate to, so the support groups that were supposed to help her during this difficult time only made her feel worse about herself.

An Indigenous author from Australia who wrote about her experiences with breast cancer identified problems with bureaucracy when addressing colonizing issues, stating that "[t]he government must come to the fore and help us. They've been side-stepping the issue. OK, they've funded Reconciliation to the tune of fifteen million dollars. Stolen generation people – we don't get that. And that's where the need is. We need healing and facilities". (131)^{p.147} The notion here is that, instead of continuing to give money to those at the higher societal levels, implement free medical care for those diagnosed with breast cancer to cover the cost of their prosthesis, prosthesis products, travel expenses, and time off work. These are the areas where money needs to be allocated for proper resource management.

5.1.1.3 Post-surgical Accessory Support

"We didn't have a lot of money and medical services wouldn't approve. I don't know why. I've never had a prosthesis before so we went out and bought it - \$450.00 and \$75.00 for a bra - then we sent the papers away and they turned me down. The worst thing is it's going to be five years, I had only just ordered one. How could any woman, especially if you don't have a lot of money, and I don't have a lot, so that means they go through a lifetime of just having one prosthesis. That's bad and maybe that should be looked at - make sure that they are taken care of after [their surgery]." - Norma

A previous study in Saskatchewan on Indigenous women with breast cancer found that many participants were concerned about their economic needs in relation to breast cancer, specifically prostheses, brassieres, and medications. (14) One participant even stated that she spent more time worrying about how she was going to afford to pay to be sick rather than focusing on the cancer itself. (14) Similarly in this study, the women often felt that their medical needs were not supported through Canada's healthcare system especially their financial needs.

The quote above refers to medical supplies such as prostheses and specialty brassieres for women who had mastectomies. Furthermore, some of the women also mentioned wanting to be subsidized for taking time off work to seek traditional healing, which can be quite a rigorous process in and of itself. The process often includes gathering tobacco and/or other gifts, travelling to an Elder who is more likely to live in a rural or remote location, and spending quality time receiving Indigenous healing. None of this was financially supported by the healthcare system, which was concerning to the women who wanted to take a more traditional route in their treatment. There needs to be policy implemented to subsidize low income patients going through cancer treatments.

5.1.1.4 Summary of Socioeconomic Status

Socioeconomic status plays a large role in the decision-making process around breast cancer treatment and includes factors related to social determinants of health. Social determinants of health are the conditions into which individuals are born and include social factors that influence their health, such as housing, education, employment opportunities, and accessibility to appropriate healthcare services. (2,55) For example, Indigenous cancer patients might not have the financial resources to travel or pay for treatment. (30)

The women often had many responsibilities and their socioeconomic status heightened the stress of a breast cancer diagnosis. Financial support would have helped alleviate the responsibilities they had at home and allowed them to spend more quality time on themselves (by seeking traditional healers and/or paying for their own medical expenses). In other words, choosing what treatments they wanted to pay for. Stress about finances played a major role in the decision-making process around breast cancer treatment and the healing journey of their choice.

Women without financial support often lacked the quality of care they needed to heal and make treatment decisions around breast cancer.

Some Indigenous women have identified being poor as a reason they have encountered problems in the healthcare system. (50) This is because subsidization does not occur for patients of lower income going through cancer treatments. Some of the main factors that influence doctor-patient relationships are social relations, which are often not visible but quite profound in these interactions. (62) This is important because Indigenous women often have difficulty accessing healthcare services due to lack financial support, so healthcare decisions typically are not made based on health needs but are instead based on finances and the ability to pay for services. (50)

Importantly, any coverage for expenses should not be given through reimbursement because many of the women would not be able to pay these fees up front; in other words, they would still lack access to the resources they need due to improper structural issues. A woman's first thought after being diagnosed with cancer should never be "I can't afford this", especially in a nation that prides itself on its healthcare system and a province that pioneered public healthcare. Indigenous women's socio-economic status should be prioritized if there is to be any substantial change in this population's health status.

5.1.2 Theme 2: Introduction to Access to Health Care Services

"Because it's hard to get in to see good doctors. They have a walk-in clinic, and it's hard to get a doctor. You have to be really pro-active in getting access to services... But we also need better access to doctors. You know how hard it is for people to have access to a doctor here. And a lot of them, it's the walk-in, revolving, walk-in clinic, so your file never gets looked at by your family doctor... Absolutely no [continuity], especially in the health centers in the North, because

I work out of Wollaston, and it's just insane up there, my god. I feel sorry for people up there. The doctor comes in twice a week... they come in and they see the patient for whatever, whatever is the problem at that time, and then the nurse follows up with the medication, and by the time a lot of these people are diagnosed, they are stage four. You know, we can do all the awareness and prevention stuff, about breast cancer, this cancer, that cancer, but until we – until First Nations, I'm just talking about La Ronge here, or even the health centers, until they - can have the same kind of access to a family doctor like everybody else in this country, then these things are going to be missed. By the time people we are diagnosed, it is way too late, and it is going to cost a lot of money. Now, they're going to have to do the surgery, the chemo, all these other treatments, right?" - Danika

Access is an essential aspect that needs to be addressed for the improvement of Indigenous people's health status. (58) Accessibility, in this case, included three main aspects: knowledge, location, and travel. Some Indigenous patients disliked spending time away from their home town and family for cancer treatment. (117) Women living in rural and remote locations, especially in northern parts of the province, often dealt with different doctors coming into their communities instead of having one family doctor who they could trust and build a personal relationship with over a longer period of time.

Accessibility was mentioned by many of the women as a huge issue that strongly influenced their decision-making process for breast cancer treatment due to the fact that equitability is not happening in the healthcare system. Those with lower education and those further from urban centres with large healthcare facilities specializing in cancer are not able to make choices; instead, a choice is forced upon them mostly because it is too late by the time they receive the care they need.

As mentioned by Danika, she makes it pretty clear that Indigenous peoples do not have the same level of access to healthcare services as other people in this country. She stresses the importance of having proper access to catch breast cancer at an early stage so it can be diagnosed and treated before it gets to the point where it is too late. She also mentions how preventative strategies are useless, in this sense, unless the healthcare services are readily available and Indigenous peoples have the opportunity to build a relationship with their physician so they are more likely to trust them. Another important point she makes is that, when cancer is caught late in the disease process, it is not only costly for the patient but also for the healthcare system as a whole. Having access available from the beginning would save more money and lives in the long run. The theme of accessibility included knowledge, location, and travel.

5.1.2.1 Knowledge

"Throughout the process I had always thought about Elders, those that might be twenty years older than me, even ten years older than me, some of them even my age that haven't even got close to the education that I have. They're not going to understand their treatments. They're not going to understand their grades, their stages. They just are not and I see it now even in the groups that I belong to." - Carol

Accessibility, in this study, not only included physical access to healthcare services but also knowledge about the disease. We know that lower levels of formal education and lower socioeconomic status leads to limited access of information and knowledge about cancer. (31) Access to knowledge, in this sense, was impacted in terms of understanding medical terminology, language barriers, and general familiarity about the disease (i.e., stages, genetic predispositions, and post-surgery consequences/options). Some of the women mentioned concern for other Indigenous peoples, especially if they were older, because they either did not speak

English nor understood the medical jargon used by their healthcare providers. Many expressed a need for healthcare staff to explain things in layman's terms, and also stressed the importance of having an Indigenous liaison present in the healthcare setting for proper communication and culturally appropriate care to assist in bridging knowledge systems (traditional, western, and two-eyed seeing).

Access is an important social determinant of health, in that access to healthcare services has a positive relationship with an individual's health status. (58) In a study by Roanne Thomas on Indigenous experiences of cancer, one participant emphasized that "[t]he surgeon who speaks to you, the doctors, the medicines you're taking... the words they use are commonplace in their daily life, but in ours, they're not". (133)^{p.1} Similar experiences were expressed by the women in this study, indicating that access to knowledge is a concern and a barrier that needs to be overcome, particularly for Indigenous women making decisions around breast cancer treatment.

5.1.2.2 Location

"I'm a healthcare professional so I know the system but if you're from out of town and you don't know the system, I think that's huge. You know I was fortunate; I lived in a big city, but for people from out of town, no place to stay, especially people from a reserve in the north or wherever, I think it would be very daunting. I think they wouldn't ask questions whereas me? I'll ask questions, so our story is a little bit different I think." - Gina

Place of residence was another important barrier the women faced in relation to the decision-making process around breast cancer treatment. The women also had difficulty accessing prostheses and prostheses products post-surgery, which were only available in Saskatoon.

"She [the nurse] talked about the Pink Tree but that's in Saskatoon and you have to call and make an appointment so you can get fitted for a bra and prosthesis and whatever and I said, "Okay but how am I going to get there?" – Ruth

There is a clear need for more equitable support for women living in rural and remote locations who need to travel outside their communities to receive the same level of care someone from an urban centre would receive.

5.1.2.3 Travel

"The travel back and forth. I had good places, you know – the Band paid for, or whoever, Health Canada – they paid for everything, so my place of stay was quite nice, but it's that travel back and forth, because sometimes it was quite painful to travel. We [my husband and I] used to stay one night after the treatment and then come back the next day... I think if I wasn't with my husband I'd be having a really difficult time. Because, it's the traveling, you know? For the northern women... It's a long trip." - Mary

Traveling was also another barrier related to access in the decision-making process. For women in the northern regions specifically, travel was very isolating. What was regularly a very long trip became all the more exhausting following chemotherapy or radiation. The women found it difficult having only one treatment location in Saskatchewan because the trips to Saskatoon and back [to their communities] were very costly and time consuming. Thankfully, some of the traveling costs were covered; however, the time spent on the road when they were sick was very difficult and made the cancer experience that much more painful. Policies need to be implemented to make healthcare services around cancer treatment more equitable for those living in rural and remote locations, such as covering travelling expenses and paid time off work travelling for treatment.

This is especially a concern for women who are single or widowed and do not have the same level of support while traveling for treatment. Being far from home not only strained patients whose limited income became intensified when travelling to healthcare centres but also added stress to their healthcare experience by distancing them from family and friends. (86) A previous study noted that some cancer treatment centers were over three hours away from the women's place of residence, making time away from home and family very difficult. (28)

5.1.2.4 Summary of Accessibility

Patients who report issues of money or transportation when seeking health services are more likely to present with breast cancer at a later stage in the disease. (34) For those participants who travelled long distances for treatment, especially for those who came from the La Ronge region, accessibility was a recurring theme in their cancer experiences. They expressed concerns about the lack of many healthcare services in their community, including cancer screening, having a family GP or regular physician, emotional support, and breast cancer supplies such as specialty bras, bathing suits, and other prosthesis products. Given this lack of resources, the women were more likely to delay their treatment choice, which puts them at greater risk of dying from breast cancer.

5.1.3 Theme 3: Introduction to Culture Identification

Culture tends to have a significant impact on the decision-making process around breast cancer treatment. According to Ellerby et al., "spirituality and cultural understandings of death, loss, and the existence of Spirit Beings often play[s] a role in the bioethical decisions of [Indigenous] patients and families". (54)^{p.846} The subthemes related to culture are diversity, which can be viewed as traditional, western, or a two-eyed seeing perspective; and stigmas around cancer which was strongly linked to silence around the disease.

5.1.3.1 Diversity

"...every woman, well every diagnosis – especially breast cancer is different. It's going to be a little bit different." - Danika

Although there is a common misconception that Indigenous cultures are very much alike, they each have their own set of customs, beliefs, and traditions. (40,87) It is also important that two members of the same Indigenous community are not to be assumed to share the same values, beliefs, or approaches to health and illness. (87) Because of the diverse perspectives of Indigenous patients who chose traditional treatment, western treatment, and/or a combination of the two, a patient-centered approach is the best paradigm to take in providing quality care. (86)

5.1.3.1.1 Traditional

"I have a lot of friends that have grown up very traditional as well and like one – one in particular her dad had diabetes and had to have both of his legs amputated from the knee down. They [the traditional Indigenous peoples] insisted because – that's the way they were raised you know that our – there's a belief that our spirits will wander the earth if we're not whole, you know given back to Mother Earth, right? So it was just kind of – well I didn't know what I would do with them [my removed breasts]. I thought you know if I, put them in a freezer or did something so that when I do leave this earth it – they could just come with me but, I understand that there's a tumor bank which I did not know prior to. I asked I think at some point I said, "What do you do with – what are you doing with them? You know do they just go in a heap do you throw them out?" Like what do you do? Like you take the tumor I understand, but it was just a question of where they went, and I never did get an answer to that." - Tara

Some western medical practices went against the women's beliefs with respect to the interconnectedness of body, mind, and spirit. (28) This was mentioned by Tara as the holistic

belief of the physical, mental, emotional, and spiritual aspects of the self where the physical body also contained the person's spirit. She mentioned how removing tissues such as the breast, or part of it, was like removing a part of your spirit; in order to connect it back properly the tissues needed to either be burned or buried, during a cultural ceremony. She was aware that conducting genetic tests on the tissue was also important for being well-informed about the survival of her children and grandchildren (as she had one of the genetic mutations herself); however, she would have preferred to at least be given the option of having her tissues given back to her after the genetic testing, so she could continue the healing process. The removal of cancer including the amputation of body parts, threatens the women's identity and their place in society. (28) This is because holistic values of the body being something sacred were a part of some of the women's personal identity, and so played a large role in how they made decisions around cancer treatment.

Holistic health, in Indigenous communities, primarily revolves around notions of holism, interconnectedness, and balance, as well as the integrated aspects of community, family, the environment, and the land. (14,52,54,74,134) From this perspective, Indigenous health and healing is largely linked to, "... physiological, psychological, spiritual, historical, sociological, cultural, economic, and environmental factors". (14)^{p.68} There is a full connection between the physical, mental, spiritual, and emotional aspects of the self and a person is healthy when all are in balance. (50)

Spirituality is considered to be a central element of being healthy from an Indigenous perspective. (40) As one Indigenous participant mentioned in a previous study, "...this healing journey was not only for the physical part of my body but also my emotional and spiritual...Before we can heal your body, we have to heal your mind". (88)^{p.18} Furthermore, Indigenous values are generally based on, " holism, pluralism, autonomy, community- or family-

based decision-making, and the maintenance of quality of life rather than the exclusive pursuit of care". (54)^{p.846} In other words, "to be healthy means to feel good with my spirit and with my heart". (88)^{p.20} Numerous non-western cultures view health in similar ways wherein the individual is a relational, interdependent being; this is quite the opposite of the western biomedical view of the self as a separate, unique entity. (52) Disease, then, is viewed as an imbalance between the individual, society, and the spiritual realm. (52) Because traditional Indigenous views of health vary from the dominant medical system, decisions around cancer treatment can be very different for an Indigenous compared to a non-Indigenous person.

5.1.3.1.1.1 Hair

"...the night before I had to go to see the doctor, and it was about the chemotherapy hey? I woke up my husband, I was crying, and he said, "What's wrong? Why are you crying?" I said, "I don't want to have no hair." He said, "Oh for f___ sake Norma, you've got bigger things to worry about than having no hair," he said to me, eh? I said, "I don't want to do that." He said, "Well what are you going to do then?" and I said, "I'm all for traditional medicine. I'll go every week. I will make myself better. I will but I don't want chemotherapy. I don't want radiation." He said, "Then you don't have to," so we went back. We told the doctor[s], and they said, "Okay we'll do it with medication." That's why I have to take so many pills [to take now], you know?" – Norma

In some Indigenous cultures, cutting one's hair is a sign of grief and is typically done when a loved one dies; representing the loss of a part of one's self. (135) Cutting/losing your hair can also mean that someone in the community, or in your family, is going to die soon. (136) During my time at White Cap Dakota Nation, I was even told that braiding one's hair is a spiritual practice in itself where keeping it long, at the bottom of your head, and braided

represented an extension of you. It is like an umbilical cord connecting your brain/head to the Creator so when you braid your hair you are connecting yourself to a higher being. Hair, then, is only meant to be removed when the death of a loved one occurs. For example, you cut and bury your braided hair with them so your spirit can be with them always. In a previous study on Indigenous women's breast cancer experiences in Saskatchewan, some of the women who cut their hair would smudge their cut braids to ensure that their hair would grow back eventually, once their bodies were healed after their cancer treatments. (136) Although hair is an important part of their culture, some women felt uncomfortable mentioning their hair in cancer support groups (136) and others chose not to go through with some western treatments altogether due to the fear of losing their hair.

In fact, one of the ways that some of the women's family members showed support was by cutting off their hair as well, and this meant a lot in terms of support because it symbolized them going on this journey together. Aspects of cancer treatment related to hair were important for the women to be informed about and appropriate support then provided, because hair represents such a powerful part of Indigenous culture.

5.1.3.1.2 Western

"I would just say I'm on kind of modern versus traditional medicine. My one story about this is my cousin's wife had breast cancer around the same time I did. It was about the same size I think, her tumor, and she decided to treat it only with traditional medicine until it was too late. Then she died probably within two years anyway... No. I wouldn't say so [that Indigenous spirituality helped me at all]. I'm not a terribly spiritual person." - Erika

Some women described the two world views as dichotomous with a differentiation between "our ways" and "their ways" that makes identifying with the healthcare institution very

difficult. (74) Furthermore, the women's personal experiences as a cancer patient, or a witness of family or friend's struggle with the disease, influenced their decision to actively seek and undergo treatment. (28,50) Previous studies report that Indigenous people's decisions to interact with mainstream healthcare services varies; some choose to have minimum contact with western treatments or 'white ways' and others, particularly those who are younger, choose to embrace western medicine. (40) I would also argue that those who grow up in urban centers, or who have higher levels of education, are also more likely to follow western treatments for their breast cancer. This is because they understand how and why these treatments work, or because they experienced the death of a loved one who only chose traditional treatments and did not survive the cancer.

5.1.3.1.3 Combination of Indigenous and Western Beliefs

*"...after they told me there was a change [with my breast cancer] ... they did scans and all that they said that it was important for me to get the surgery done but at that time I just... I kind of I was going to say, "No it's okay I don't, I could deal with this. I'll go back and drink my tea," and whatever. I told my brother and right away he made me some [tea] and then I said, "Well what do you think? Should I go for the surgery?" And he said, "You know what? You do what you feel is right," he said... "We could do it with the western and our traditional [way]. They could work together." He said "Gineecoo (Ojibwa). It's up to you" he said, "It's up to you."
– Laura*

The notion described in the above quote was also suggested by a participant in another study on Indigenous peoples with cancer, "[m]y mother's theory was: use the traditional way and also use the white man way. Because she says, "Both ways can help you. Don't ignore one way".(88)^{p.19} This is why it is so important for both treatment types to be supported and

developed in the healthcare system, so that collaboration can occur. (117,137) We know this information from a study taken fourteen years ago; yet there is still no policy implementation to support Indigenous ways of healing for cancer treatment within our healthcare system today. There is an obvious demand for more equitable care for Indigenous peoples and culture to exist in Canada's healthcare system.

"But now today when I talk to people who are going through that I always tell them, you know, "If you can't go that way, find somebody that you know." I said, "That's what helped me." "Everybody has different beliefs in their life," I said, "some are different like Catholic or whatever, right? I'm Catholic." I said, "I always go to the churches and stuff, but I always go that [traditional] way too. I don't want to lose my culture, where I come from." I said, "A lot times that helps a person out." I said, "A lot of people are not as fortunate as us." I said, "They don't [make it], they get defeated. They don't survive that." I said, "But for us that are going to be surviving it?" I said, "They can tell their story after; of all the barriers, or obstacles, or challenges we had to go through all that time." I said, "You know it's not an easy thing but," I said, "It's something."" - Stacey

By addressing, "what is, rather than what ought to be", (28)^{p.285} culture-centered care can take a ground-up approach to encourage cultural strengths; this is not intended to move patients away from western healthcare methods but to find a balance between the different cultural worlds. Moving in-between these two worlds (traditional and western) is something the women find they do regularly. Rather than imposing one belief system (western) on the other (traditional), it is important to support an integration of the two. (28) However, the belief that cancer is a 'white man's disease' has also been mentioned by Indigenous healers and so treatment then needs to include western medical care. (35) Traditional Indigenous beliefs cannot simply be

displaced with western biomedical perspectives of care; they can co-exist, and when both are equally supported in the healthcare system Indigenous peoples will engage more with the medical institution to conquer the disease. (31)

5.1.3.2 Stigmas Around Cancer

"Those women that do get diagnosed, I always find people – you know when I hear about somebody [that] died, and people say, "Oh they died of cancer," and I say, "What kind of cancer?" "I don't know! Just cancer." You know, it's like people here don't want to talk about the c-word; and very - right away - it's cancer, death. Cancer. Death. Cancer. Death... people are very afraid." - Danika

Indigenous peoples are more likely to have a fatalistic attitude towards cancer, with an overwhelming belief that cancer equals a death sentence and that even talking about it will bring it into one's life. (12,14,28,31,32,35,36,88) Moreover, the stronger an individual's fatalistic belief in cancer, the greater the chances he/she will not do anything to fight the disease and thus increase their risk of death substantially. (31) Furthermore, some Indigenous peoples believe that cancer is gone once it is removed, and no follow-up is required. (31) Another spiritual belief around cancer is that if you had it you did something to deserve it, and that 'bad spirits' were punishing you for your wrongdoings. (28,35) Addressing patients whose cultural beliefs see cancer as fatalistic can counteract this notion by promoting the concept that God or the Creator works through the physician to cure breast cancer. (34) As noted by one of the women in the present study:

"Yeah, yeah and then the other issue is my Roman Catholic training, I was telling my son, I said "You know, I don't want to get to the pearly gates and God says, 'But Quintan, we sent

you to chemotherapy, like you didn't go, ' so it's like I'm trying to cover both [traditional and western] sides...- Quintan

Personal and community constructs of traditions and mythical beliefs around cancer influence the decision-making process around treatment. A way to help allay fears is to reconnect with one's culture or spiritual belief system. (88) Having immediate support, whether spiritual or emotional, helped alleviate the feelings of fatalism with a cancer diagnosis. Similar findings were mentioned in a study by Struthers and colleagues, where one Indigenous breast cancer participant stated the following: "I finally called one of my friends and got a hold of her and let her know [about my diagnosis]. She talked to me and really helped me calm down a lot because I didn't know. You know, it's like, when you hear that word and you hear that illness. It's automatic. It's affiliated with death. I thought, "OK. I'm, going to die"". (88)^{p.17}

"I was diagnosed [I felt like] this is almost like a death sentence you know? Yeah you hear that c-word." - Mary

It is very important for immediate support to be available in the healthcare setting so that feelings of fear around a cancer diagnosis can dissipate more quickly to make the decision-making process less stressful and more timely.

5.1.3.2.1 Silence

"... I think a lot of First Nations people, when they hear [of cancer], and that's what they see, right? A lot of people in our communities are – by the time they're diagnosed with breast cancer, lung cancer, ovarian cancer, colon cancer – they're at stage four, and they're dead within three months... I think for me, that's what I see all the time, you know? Even when you ask somebody, "How did they die?" "Cancer," and they'll say [it] like it was so – once you have cancer, you're dead - and a lot of them, rather than deal with going through whole journey of – I

was diagnosed with cancer and you know really being a fighter, and I want to live, and you know, there's hope – people out there, we don't have that here. People are often left to – it's almost like they've died already, you know? And nobody really – or they're in their death in the hospital - nobody really wants to talk about it." - Danika

It is very difficult for Indigenous women to find someone in their community to talk to about their diagnosis and experience with breast cancer because no one talks about it. In a previous study on Indigenous women's breast cancer health, one participant noted that "[y]ou know, we grew up in a culture where the older generation didn't talk about sex". (35)^{p.381} When Indigenous peoples try to talk about cancer with their friends and family, they find it difficult to keep their loved ones engaged in the conversation. (32) The women in this study also felt they did not want to burden their friends or family with their disease. Similar findings were mentioned with respect to Indigenous women in Saskatchewan who felt that sharing cancer experiences with close friends and family was sometimes difficult because it is hard to ask for support in these situations. (14) Furthermore, they felt their friends and family could not provide them with all the support they needed in relation to the disease itself. Some Indigenous patients have even described feeling stigmatized for their illness and facing further alienation from within their community. (86)

5.1.3.3 Summary of Culture

It is important to remember that Indigenous knowledge systems do not exist in isolation of social, cultural, economic, and political conditions. (105) These knowledge systems include a spectrum of beliefs between traditional, and western perspectives. They also include myths and stigmas around the disease that are difficult to break especially when members of their community are uncomfortable opening up and talking about the disease. However, a previous

study in Saskatchewan on Indigenous women with breast cancer found that women were very interested in sharing their stories with breast cancer and using that exchange as a way of healing, and as a way to alleviate feelings of fear around the disease. ⁽¹⁴⁾ The women identified the lack of a networking process within the healthcare system as a barrier when trying to access support. Because this is such an important part of the decision-making process and many Indigenous peoples have mentioned this as something our healthcare system is lacking, implementing this sort of networking practice at cancer clinics has great potential for better quality patient-centered care amongst this population.

5.1.4 Theme 4: Introduction to Cultural Safety

Indigenous women want access to care but fear the healthcare setting does not align with their cultural needs. (28) When practicing cultural safety with Indigenous patients, it is important to understand the following aspects of patient care: "Indigenous knowledge, respect, communication, inclusivity, mentoring, and support...". (58)^{p.E6} This section contains aspects of the influence of colonization, specifically Indian Residential Schools, as well as misdiagnoses, and feeling like an outsider or stranger in the healthcare setting. Feeling like a stranger in the healthcare setting included aspects related to cultural safety, such as the influence of Indian Residential Schools, discrimination, trust, respect, communication, time, connecting, and self-efficacy.

5.1.4.1 Indian Residential Schools (IRS)/Intergenerational Effect of IRS:

"You've heard about the residential schools so much lately and I think people are just getting desensitized to it but not really understanding the impacts and how it's not [over yet], because this last school closed, it's not done yet... It's not done yet it's not about the money it has nothing to do with money. We have generations of people who don't know how to be parents,

whose lives have been disrupted and to get them back is going to take time; it's going to take time. I know people are tired of hearing about it because I hear it all the time, but how are things going to get better?" - Tara

More cultural safety practices need to be implemented in the educational aspects of all healthcare professional careers, especially for frontline workers who are the first to deal with these patients. An opinion poll taken in 2002 by the National Aboriginal Health Organization identified residential school experience, as well as the loss of land and culture, as main contributing factors to poorer health within this population. (53) This means that paramedics, administrative staff, and police officers need to take in-depth cultural training and education seminars before getting certified in their career fields. This goes back to the four main aspects of cultural safety: humility, awareness, sensitivity, and competence. (120)

Colonization and its resulting social, economic, political, and cultural marginalization profoundly impacts Indigenous peoples in Canada and across the globe. (2) Previous studies report that feelings of cultural loss due to colonization were at the heart of the decision-making process around cancer treatment for Indigenous women. (28,36) This is because colonization, federal policies, and wars have increased the vulnerability of Indigenous peoples to disease and their dependence on western healthcare for survival. (138) Furthermore, colonial structures and systems have effectively silenced Indigenous women and negatively affected how they seek out health services; this process has also been defined as an act of structural violence. (55) For example, Indigenous women's reluctance to admit pain was something taught to them by their Catholic teachers in Indian Residential Schools. (60) A previous study in Saskatchewan with Indigenous women with breast cancer also found that Indian Residential Schools influenced their cancer experiences. (14)

5.1.4.2 Feeling like a stranger/outsider

"Nobody wanted to tell me really what it was I found. I find all the stuff I'm going through might be for nothing. Maybe I'm going to die next month because they don't tell you anything, you know? They don't say, "Well this is kind of what we see." They're afraid I guess to say like, "This could be cancer and you have six months to live," that kind of stuff; but they do it for others." – Quintan

Those from rural and remote locations often felt uncomfortable in the healthcare setting, which was frequently described as a foreign and/or hostile environment and not a place of healing for them. They often described a distaste for hospital food as well as a strong dislike towards the quick-paced and cold environment. Due to this discomfort, the women were less likely to spend time discussing issues with respect to their treatment that they felt were important. Othering practices can infiltrate clinical situations, stimulating underlying power relations and assumptions about a patient's gendered, classed, and racialized locations. (56) For example, a study on cross-cultural care in the hospital setting with Mi'kmaq clients found that participants described feeling like a stranger in the healthcare setting, which was often described as the "White man's" world or going the "White man's way". (74) This might be because the western, sterile, and cold environment of the clinical setting can make Indigenous peoples feel like outsiders. (117)

This separation was often depicted more generally as a dichotomy between the hospital and the reserve. (74) This was described by one Indigenous person, who said that "[f]or generations and generations our people have taken care of each other. We don't believe or think the same way as a White man". (74)^{p16} As mentioned by Jennie Joe, "[p]art of the dismissal

might be attributed to the patients' feelings that they were "guests" and therefore not in a position to make demands or offer suggestions". (74)^{p26}

5.1.4.2.1 Discrimination

"After I got my biopsy done and I was laying there. I heard that nurse talking to the other lady and I heard them. She said, "This one's black, eh?" They were trying to be quiet, but I could hear it." - Stacey

The lack of respect and misunderstandings include healthcare staffs' lack of cultural competency, humility, sensitivity, and awareness. (120) Care that is not aligned with patient preferences and cultural understandings of care are based on racism and negative stereotyping. (87) Participants expressed times when they believed their needs were misunderstood by medical staff simply because they were Indigenous. (74) For example, one woman in the study had no idea she could chose to have reconstructive surgery, or purchase a prosthesis, until after her breast was already removed. She would have preferred to be informed about her options prior to making the initial choice of getting a mastectomy. The women were not properly informed and they had difficulty accessing proper sources of information about what to expect during and after their cancer treatments until they were already over.

This again goes back to cultural safety being properly implemented and practiced for all healthcare staff, including frontline workers. This is especially important when Indigenous patients are offended by healthcare staffs' prevention and early detection strategies because they are associated with negative stereotypes targeting issues based on obesity, diet, alcohol, and drug use. (93)

5.1.4.2.2 Trust

"I told him that there's no way you're going to do surgery on me. "There's no way that you're going to take my breast and go get a big payment for it and go sitting on the beach [somewhere]," I said at that time... I made a joke about it. But anyway I said "No I'm not, I will not" and I drank my teas and I went through the chemotherapy." - Laura

Patients often depicted hospitals as profit-driven businesses, even though they are publicly funded through a national healthcare system that is not profit oriented. (74) This probably stems from historical relationships of distrust between Indigenous peoples and the healthcare system. (58) Patients who delay, or refuse to seek, treatment might do so as a result of mistrust, discrimination, and/or previous negative experiences within the healthcare system. (82) This is a serious problem for Indigenous patients making health care decision because patients who mistrust their healthcare providers are more likely to be hesitant in sharing sensitive information with medical staff, (87) information that can help inform their decision making process about cancer care. Furthermore, cancer death and reoccurrence has been shown to lead to attitudes of mistrust in the healthcare system, which could strengthen the distrust Indigenous patients already feel towards western medicine and doctors. (31)

"Over half of the women were coming in with recurring cancer and over half of them had double mastectomies and all their lymph nodes removed and I'm thinking, 'Oh my God, there is something seriously wrong here,' and then I got the call from my surgeon. I had to go for a resection, the margins weren't clear, and this was a theme that I was hearing through the medical clinic as well. Most of the women were going back because their margins weren't clear, or the cancer was recurring, and this is the other feeling I got that was very, very wrong. Something is wrong within the system." - Bernadette

Indigenous issues of trust, including within the patient-provider relationship, might actually go beyond the healthcare setting and be intertwined with wider social, political, and economic issues. (60,62) However, patients were more likely to trust physicians when the physician agreed with the patient's healthcare choice.

"... when I talked to the surgeon, he said my margins were clear and he talked me out of going into chemo because he said, 'Would you give chemo to your dog? That's poison, and if you have the kind of results that you got, then I strongly recommend that you do not take chemo.' I went with – I trusted him." - Danika

When Indigenous women were able to personally connect to, build relationships with, and trust their healthcare providers, they were more likely to listen and follow through on their healthcare recommendations. (50,53) Other Indigenous women have appreciated that appropriate disclosure of personal experiences with their healthcare provider assists in the relationship building process, thereby normalizing the women's feelings and behaviours, lowering their anxiety levels, and allowing them to feel more comfortable expressing their concerns. (76) Furthermore, healthcare workers do not have to be Indigenous to relate to Indigenous patients; however, they do have to be committed to spending the time to build a trusting relationship. (36)

5.1.4.2.3 Respect

"If we brought somebody from Africa; if we brought them from the Ukraine and they don't speak the language [you] would – you find a way to – to treat your patients. But when it comes to Indigenous issues for some reason, there's just a – there's just a shut-off valve out there somewhere where they just – just turn off all kinds of feelings and that's what it feels like it's like; it's just really unsafe. Like, a French accent is so cool and an Italian accent is so cool, you know people want to hear it. But when it comes to Cree or Indigenous languages, all of a sudden

it's not so cool, you know? I'm not saying that they – they need to be cool but they should be respected and they should be treated the same way you would treat anybody else, you know?" -

Tara

Respecting local values, traditions, and the decision-making process from an Indigenous perspective is essential when communicating across cultures in the healthcare system. (40)

Receiving more equitable care is a respectful way to treat Indigenous patients, especially by genuinely listening to their concerns, and taking adequate time to go over all their concerns and questions. (87) Other studies conducted on Indigenous women's encounters with mainstream health services identified respect and trust as being more important to them than their healthcare providers' clinical competence. (50,60) Some of the ways that Indigenous patients have described feeling respected and understood in the healthcare setting are being treated with kindness, having healthcare staff be more accepting of family visiting, and being treated as equals. (74)

5.1.4.3 Communication

"So today I find that the women that are around here have nobody to talk to except how we find each other because somebody told them I had cancer... There's no information out there... there's nobody here [in the healthcare center] to talk to and everybody you talk to, they just sit there and listen and walk away. It's not effective in any way..." - Ruth

Effective communication is recognized as an important contributor to successful health outcomes. (32,77) Communication has the ability to bridge gaps among healthcare providers, family members, and patients, allowing the decision maker to become more empowered to engage in their cancer care. (139) Additionally, Indigenous cultures have very strong oral traditions where verbal communication is important (40); however, healthcare staff also need to

informed about non-verbal cues so respect and trust can be built. (53) For example, communication can become difficult between Indigenous peoples and healthcare providers when, for some ethnic groups, it is not customary to make direct eye contact or have open discussions about sensitive topics (41,140), such as cancer.

"My fear is for those people that don't feel like they can [speak up for themselves] because they've been raised to respect authority, you know and that in whatever form that that came in, so if this doctor who's not paying particular attention maybe or not caring to continue to look further to question, yeah 'cause that's where the - you know we need to make the changes like right there." - Tara

The quick-paced environment and excessive workloads in the healthcare setting make it challenging for Indigenous patients whose histories, social status, and past experiences shape their ability to speak up. (56) Quiet communication patterns and indirect eye contact are typically done to show respect for the healthcare provider; however, this can be viewed by the physician as the patient being disinterested, disrespectful, or showing inadequate knowledge on the topic. (28,87,121) Healthcare staff should understand that Indigenous women oftentimes feel ashamed in the healthcare setting due to Western medical practices violating their inner sacredness of being a woman, wherein their discomfort is expressed through silence. (28) For example, a study by Annette Browne found that an Indigenous nurse described the quietness by Indigenous women as a learned interactive pattern that has been engendered by patterns of paternalism and authoritative characteristics of relationships in the healthcare setting. (56) She describes their behaviour as "... stem[ming] from [Indigenous] people[s] being told how to live, how to speak, what language to speak, and that has gone on for so many years". (56)^{p.2169} This was further emphasized by an Indigenous patient in another study who mentioned that it "says a lot when

you are silent as First Nations because you're thinking about what's being said and you need to give the right answers back". (53)^{p.343}

Indigenous women have been socialized not to reveal their problems to "others" (76), making engaging in conversations around breast cancer difficult. As Dodgson describes, "[i]t hasn't been that long ago that we lived in our traditional ways. We're not used to... having somebody look at you to see if you're healthy or not". (40)^{p.344} This is why including Indigenous speaking translators and healthcare navigators within the healthcare system is so important; they become a type of cultural broker (41) who can help improve the decision-making process for Indigenous patients going through cancer by dealing with the practical aspects of treatment, which are essential to patient care. (30)

5.1.4.3.1 Language Barriers

"As your patients come from, like more isolated areas and where the Indigenous language is more [prevalent] and they live more traditionally; I think those issues are something that have to be considered in that way. Like my Aunty F_____ A_____ and I sat around like they worked on a – a dictionary of medical terminology to trying to – so they could explain to patients that were come from – from the North you know. 'In Cree, how do you say that?' It's – Munchoosuk, when you think about how cancer's described – because Cree is very descriptive. I mean it's like worms, worms that are eating away at you right?" - Tara

People who do not speak either of Canada's two official languages (English or French) tend to receive inappropriate healthcare. (58) For example, many English words and biomedical concepts do not accurately translate to Indigenous languages, making direct translations difficult (41) and therefore questions and information shared about cancer might not make sense to some Indigenous patients. An American study found that Indigenous patients expressed concern with

physicians cutting off Elderly patients when they wished to have more information about their health issue and, in general, not having complete explanations of their condition or treatment plan. (93) Another study suggests that language barriers and health literacy within Indigenous communities has been one of the major issues, especially among Elders, in participating in cancer screening (141), and can be compounded with problems in the public health dialogue (137). Indigenous cancer patients can also have a stronger preference for traditional instead of western treatments (88,117), meaning that improperly trained non-Indigenous medical specialists might have difficulty effectively communicating with Indigenous patients and their family members. (30)

Ellerby et al. identified seven aspects to improved communication with Indigenous peoples: respecting the individual, practicing conscious communication, using interpreters, involving the family, recognizing alternative approaches to truth telling, practicing non-interference, and allowing for Indigenous medicines within the healthcare system. (54) Furthermore, communication patterns with Indigenous patients have been most effective when practicing "...patience, comfort in silence, listening, storytelling, and humour". (86)^{p.20}

5.1.4.4 Time

"You know what? Information is so powerful, is what it is so had –for example - my very first needle biopsy had I known, okay it's going to take some time to get these tests back. Typically they take about X – This much time. That would've been helpful too; like not hearing that [timeframe] was horrible... The waiting is what was killing me, I understand now that it really wasn't that long but it feels long... so when he [the doctor] called me into - you know give me the results and - by that point I think I nearly grabbed him by his shirt and [was] just like, "I need to know, like this is enough", I said, "I'm going crazy!" - Tara

Reducing long wait times would keep Indigenous patients' anxiety levels lower and encourage them to continue medical treatments and checkups. (76) Longer doctor visits also allow for more attention to facets of care such as increased patient education and participation. (53) Previous studies on Indigenous women with breast cancer found that wait times and the time spent waiting after a cancer screening were extremely long [sometimes up to 3 months], which was too long for participants to wait for such important information. (35)

"I actually phoned my sister S___ and she says, 'Well whatever you decide.' Then I ended up phoning his [my husband's] mother, and she just said, 'Well if it were my option, I would go both [double mastectomy], right?' But it was a matter of 45 minutes they gave me for this life-changing decision." - Mary

Indigenous patients also feel that the doctor-patient encounter is very time pressured in the healthcare setting, making it difficult for them to receive adequate information about their condition; this is especially the case for Elders. (93) Another reason time might be a barrier for Indigenous patients is because some Indigenous peoples have a different cultural understanding of time, which may cause difficulties within the typically quick-paced and rushed environments typical of the healthcare system. (53,86) For example, many Indigenous patients take a considerable amount of time to make decisions about treatment options because those decisions need to be made through a consensus with their family and community members, outside of the healthcare team. (87) However, the time between the doctor's communication and the patient's understanding of the decision is crucial in quickening the decision-making process around breast cancer treatment. (142)

"Yeah. I went up there and I don't know why I was five minutes late but I was five minutes late arriving and they said, 'Yeah sure, have a seat,' and I sat there for forty-five

minutes and then I went up there and I said, 'My appointment was at 11:30,' or something like that and the one girl says, 'Well you arrived at 11:35 so we had to bump you up.' I said, 'Well you have to tell me that; don't just leave me sitting out there for forty-five minutes wondering what's going on.' ... I said, 'And five minutes late should not constitute me waiting for forty five minutes. Everyone who has come in the door has gone ahead of me.' 'Well they have appointments,' and I said, 'Well my appointment was 11:30 and I was five minutes late' ... but I thought, 'This is too weird.' It's like a penalized system. You can't be five minutes late, they will penalize you. You sit there for an hour." - Quintan

Another study found that Indigenous women have described waiting excessively long periods of time for being a few minutes late in the healthcare setting, which represents another form of penalization. (60) Furthermore, healthcare professionals disregard the personal situations of low income patients by assigning fines to patients who missed appointments or arrived late. (87)

5.1.4.5 Connecting

"We're looking for each other, we're forced to look for each other and I don't think that's right..." - Carol

Most of the women felt comfortable telling their cancer story and wanted to help others on their cancer journeys; however they felt that there was little support for them to connect with others within the healthcare system. A previous study in Saskatchewan on Indigenous women with breast cancer found, "...that support was related to the inter-connections among emotional and informational support, economic survival, racial barriers and environmental concerns".

⁽¹⁴⁾pp.66 Perhaps a program could be established to provide a networking type of support that connects newly diagnosed Indigenous women with other Indigenous cancer survivors. This could

help alleviate some of the stress in the decision-making process around cancer treatment. It could also provide some additional support, which all participants wanted more of, especially from someone who had been through it before, and with whom they could relate.

"I said, 'I need to think some things through,' I said, 'I don't know. I don't know what to expect. I don't know anybody that's been through this, you know, that could guide me along what it is I need to do.'" – Stacey

Similar findings of feeling lost in the healthcare setting were mentioned by other Indigenous peoples with cancer who, in a previous study, stated, "I need a map. I know where I am but I don't know where I need to be". (133)^{p.2} Furthermore, there are substantially higher levels of emotional and mental stress compared to intellectual or physical distress during the pretreatment period, which suggests a need in the healthcare system for these issues to be addressed and supported immediately so patients can quickly make decisions that are best suited to their needs. (143) Perhaps if a networking protocol was established within the healthcare system, the decision-making process would be less difficult, less stressful, and maybe even happen in a more timely manner. It would allow the women to feel more comfortable expressing their concerns, build their self-confidence, knowledge, and level of self-efficacy so they are able to discuss things more easily with their healthcare providers.

This networking process would also assist the women in addressing any social or cultural issues that may arise during the decision-making process around breast cancer treatment. For example, an Indigenous woman losing her hair during chemotherapy is very important and learning how to cope with that should be implemented within medical protocols. Additionally, if the woman prefers traditional treatment, western treatment, or a combination of the two it would be easier to talk to others who have went through this before. It would also allow the women an

opportunity to discuss who they would like to talk to; perhaps decide which doctors are more respectful of their traditional practices, how to tell their family about their diagnosis, how to get financial help, and how to cope with their loss of femininity.

5.1.4.6 Self-efficacy

"I thought, "I'm on a high-risk program. Why do I have to phone and phone and phone and phone for an appointment?" I waited for six months, and they apologized profusely, but I'm thinking, "What the hell kind of program is that where I have to be so very active in my own treatment and following-up and making sure?" – Gina

Self-efficacy is defined as "...the ability to strengthen one's mind, body, and soul through personal efforts or with the additional force of spiritual sources of strength".(73)^{p.36} The women in this study all had high levels of self-efficacy. This was particularly evident as four of them were actually misdiagnosed when they first went to the doctor about their breast cancer but kept pushing for a second opinion. If they did not speak up for themselves, their breast cancers would have gone undiagnosed and their cancers would have gotten worse, increasing their risk of dying from the disease.

"... I told Dr. L _____, "I'm not leaving here today to come back next week. I want to know today that I have breast cancer, before I leave this place." - Danika

The women had to be quite aggressive when requesting their own medical diagnoses. Additionally, they described these misdiagnoses as negative experiences where they felt insulted, disrespected, and unheard. In one case, the doctor told her that a patient that her tumor was just a fat gland.

"I went to see a doctor in North Battleford and he felt that lump and he said, "Oh I wouldn't worry about that if I were you Stacey. That's just a fat gland," and I said, "Oh, okay,"

but that pain wouldn't go away, right? So my husband found me a [second] doctor. He said, "I found you a doctor and you go see him." He found me somebody different, and I went that time. That was in March I saw V_____, and he's been my family doctor ever since eh? He did a complete physical on me, and he told me about that lump. Right away he said, "You need to get an ultrasound done, and you need that mammogram done." - Stacey

In another case the doctor insisted (with 99% certainty) that the patient did not have breast cancer.

"[I had] a needle biopsy in the doctor's office - and I had to convince him because he was just not - he wasn't comprehending is what I understood. [He wasn't thinking cancer] at all he's like, "I'm - I'm 99% sure that this is not cancer, so we'll just do a needle biopsy here in this office." - Tara

One woman said her doctor asked her if she had fallen (onto her breast) when she was referred to the clinic due to a lump found in her latest mammogram.

"I went to a doctor and December 24th is when they diagnosed me with this lump on my breast. At the S__ R__ clinic, the doctor that they called in didn't seem to know. I don't think he knew anything because he says, "Oh did you hurt yourself? Did you fall?" I mean they're going on the ultrasound thing right [at an ultrasound mammogram clinic] "What looks like I fell?!" You know, and so I just said, "No..." I said, "I have a lump on my breast, it's in there somewhere," and that was it and then I left there. I thought, "That guy doesn't know what he's doing, he doesn't know who he is, I wonder if he's [even] a doctor?" - Quintan

Another woman delayed treatment for over a year because her doctor told her it was nothing.

"... that's how I think a lot of these other women [are], they could have prevented the whole breast being gone because they're scared to go see the doctors because they're going to get a run around anyway and they don't make an appointment for you to see a specialist in Saskatoon or Prince Albert or anywhere. It takes about three, four months, or six months to get a referral and then by that time it's too late, they lost their breast. See if I had, if the doctor had listened to me the first time, if he had sent me to get a mammogram done the first time my breast started hurting, that was a year. He waited a year." - Ruth

Some of the women mentioned that if the doctor would have just listened to them and their initial concerns the first time they went for an appointment, their breast cancer would have been treated earlier and perhaps losing their whole breast could have been prevented.

These misdiagnoses made the women feel like they were not being taken seriously. This resulted in them expressing issues of mistrust and inappropriate encounters with their healthcare providers. This impacted their decision-making process because it often deterred or delayed their initial diagnoses as well as subsequent treatment sessions, making them feel like they were not being listened to, lessened as a person, and disrespected by healthcare members in positions of authority, specifically those who should have been looking out for their personal well-being.

5.1.4.7 Summary of Cultural Safety

Indigenous women face wide systematic barriers resulting from colonization that affect their level of trust with healthcare providers; these are based on their personal experiences with non-Indigenous policies and discriminatory treatment (76), including intergenerational trauma and historical grief (40). This grief and trauma has been passed down through stories and parent-child interactions wherein it becomes internalized and creates an aura of mistrust between Indigenous peoples and outsiders, including healthcare providers (40). Because some doctors in

the past were involved in a plot to kill Indigenous peoples as part of a government plan, feelings of mistrust connected to Canada's historical legacy remain within Indigenous communities.

(40,53)

Experiences and/or memories of colonization significantly impact patients' comfort levels within the health system. (87) Even the literal brick and mortar of the biomedical buildings can remind many Indigenous peoples of similar buildings that resonate horrific memories of bureaucracies from their past. (20) For example, one participant in a previous study noted that "[t]o me when I look at the hospital, it's no different than looking at the residential school building. What they represent it's not good and so they're gonna (sic) have to work damn hard to convince me, and other folks like me, that, that they've changed". (20)^{p.1668}

Residential school experiences also created a sense of abandonment and anonymity, which were experienced in the past but remembered in contemporary interactions with physicians. (53) This sense of abandonment might be how Indigenous peoples, especially those living in rural areas, still feel due to the frequent rotation of doctors treating them; this means that relationships struggle to be built and maintained between patients and their family doctors. Additionally, there is an underlying belief that current illnesses have been brought on by European colonists (40), with many describing cancer as 'white man's disease' (35,79,116). Although many healthcare providers believe their relationships with patients are culturally appropriate, many are unaware that their practices can unintentionally portray discrimination towards their patients; this might be because culturally appropriate care is not generally a priority in the post-colonial education and healthcare system. (55)

Health Canada has begun to recognize the importance of considering both Indigenous and mainstream sources of information when making informed health decisions. (19) Respecting

local traditions and values while connecting Indigenous peoples to community health networks is vital for providing quality care. (52,86,105) Establishing a presence in the Indigenous community is also an essential way to build trust with community members. (141) Additionally, empowering Indigenous patients has the potential to increase their level of trust and reduce their level of fear within the medical system, which is an essential step to increasing their level of care in the healthcare setting. (30) Patients that felt the healthcare system was not culturally congruent were reluctant to communicate their concerns and symptoms and had a decreased likelihood of returning for further testing. (87)

Trust between physicians and Indigenous patients can be built when an ample amount of time is dedicated to their interactions, including time for the physician to get to know their patient personally. (53) Another way Indigenous women have described an increase in trust in the healthcare system is by attaching an Indigenous women's health centre to an existing Indigenous agency, one with which they are able to be comfortable and establish a strong relationship. (76) Additionally, providing emotional support for patients might encourage them to express their values and preferences with their physicians. (132) It would also be extremely beneficial if healthcare providers knew about traditional health beliefs (121), or at least some experts in the field they could refer their patients to for additional information. Indigenous patients value a non-discriminatory attitude and compassion in their healthcare providers more than their healthcare provider having cultural knowledge about Indigenous peoples. (74)

Chapter 6: Women-Informed Recommendations

6.1 Introduction to Women-Informed Recommendations

Developing appropriate primary and secondary preventative strategies is important to properly monitor cancer occurrence in Indigenous populations (27), especially through initiatives that come from the communities themselves. Indigenous health outcomes will only improve when Indigenous "...knowledge, voices, and opinions are allowed to inform policy, research, and service delivery...". (36)^{p.1317} A health promotion perspective will be more valuable in attaining an understanding of how the healthcare system can work with Indigenous patients to better integrate the knowledge systems of traditional and western understandings of health and healing, thereby improving health outcomes. (52) From a traditional Indigenous perspective, health is accepted as a state of balance or unity that spans the physical, social, mental, and spiritual aspects of a person's well-being, rather than focusing solely on the absence of disease (52).

Using the Indigenous perspective of how decisions are made in the healthcare setting can even help develop culturally competent strategies for immigrant communities who also face cultural and language barriers. (41,55,86) For example, Indigenous ethics in the healthcare setting are important because of the great potential for addressing more generalized understandings of bioethical practice within Canada's increasingly diverse population, which has various clinical and sociocultural backgrounds. (54) For example, similar to how barriers exist with traditional Indigenous medicines being supported in the healthcare system, traditional Chinese medicine is another treatment option that patients might want to explore as a cancer treatment option; however, both approaches lack the clinical research evidence that is required for healthcare professionals to refer patients to these options with confidence. (144)

Additionally, providing more information on complementary and alternative medicines (CAMs)⁵ during cancer treatment would add value to the healthcare system as a whole. Many patients are already seeking these options out, with little understanding about them and how they might interfere with conventional or western treatments (145), so it is important to join the two knowledge systems of western and traditional treatments so patients are able to use either, or both, within their treatment plan. More research should be conducted in this respect so that all patients are able to have better access to CAMs.

Healing has often been described as holistic, addressing the person as a whole being rather than just focusing on the disease itself; this is important because, as many women have expressed, the cancer is also a part of them. As Doris Pilkington Garimara (Nugi Garimara), an Indigenous woman from Australia afflicted with breast cancer, describes, "...spirituality is connected with healing and treatment is with cure. So if the cure interferes with my healing then my treatment is interfering with my spirituality". (146)^{p.119} More importantly, she stresses the need for Indigenous women to have a choice when making decisions around their breast cancer treatment. In her book, *Under the Wintamarra Tree*, she notes that "[i]t's important, especially for Aboriginal women, to rediscover or work on their spirituality". (131)^{p.145}

"It was the rebirth of my spirituality. A lot of urban and rural Aboriginal women have no direction, no guidance now. They think the only way to go is go into a Christian church. I mean, that helps, yes, but if we had resources and facilities set up for the stolen generations people, they'd have trained counsellors. They could choose. If they want a Christian person

⁵Complementary and alternative medicines (CAMs) are defined as both the use of natural healthcare products and the process of seeking health advice from individuals who are not generally considered conventional or western healthcare providers.(96)

to counsel them, they should be able to choose that or else choose if they want to be directed and guided through traditional spirituality". (131)^{p.146}

The privilege to choose one's treatment option is very important in medical decision-making, and having those choices supported makes a big difference in health outcomes.

6.1.1 Culturally Appropriate Care

"We need Aboriginal awareness training right in the very beginning of these medical careers for people – nurses and the frontline people – those are the first people that you see." - Tara

Being culturally sensitive, having cultural awareness, practicing cultural humility, and providing culturally competent healthcare services has the potential to improve health outcomes, increase efficiency in clinical and support staff, and enhance patient satisfaction; all of which are critical components in ensuring quality healthcare. (82,117,120) For example, a 38-year-old woman living off reserve in a previous study noted that "[t]hings need to be dealt with in a completely different manner and I think maybe the nurses need to start going to a workshop on why they are there". (20)^{p.1668} Indigenous women have suggested that increasing culturally appropriate care would require the healthcare system to train staff to be informed, sensitive, and knowledgeable regarding issues that Indigenous women might face; to accept traditional teachings, processes, and spirituality in the healthcare setting; to make the clinical environment more inviting; and to hire more Indigenous staff. (76)

"There wasn't a young woman, and there wasn't an Aboriginal woman [in the whole breast cancer support group]. I tried to participate but, when I heard them talking about taking time off work and going on a holiday with their family to Hawaii because it might be their last holiday

and I was like, I just couldn't related and I – I left there feeling worse more than anything." - Tara

What is often overlooked in the first step of developing a culturally competent healthcare system is cultural sensitivity, or identifying one's own values and biases related to societal discourse. (138) For example, healthcare staff members typically fail to understand the personal circumstances of low income patients. (87) Those within healthcare institutions need to have a fundamental shift in their way of thinking by questioning their own sense of self, placement in the community, and their position in a political context. (52) Cultural sensitivity is about acknowledging personal biases and having the courage to admit and reshape them; it is *not* about treating everyone the same. (120) For example, in some Indigenous cultures looking inside the body, even in images or figurines, is considered taboo or inappropriate; therefore; it is important for healthcare personnel to learn how families and community members want to communicate information about cancer because this is crucial for spreading awareness about the disease. (87)

Cultural awareness is recognizing the differences and similarities that exist between cultures, such as languages, histories, and beliefs. (120) Healthcare professionals, at all levels, will gain a deeper understanding of traditional Indigenous medicines, practices, and beliefs by engaging with Indigenous communities directly, and taking the Indigenous Studies course. It is very helpful for healthcare providers to become involved in cultural activities within Indigenous communities to build a deeper understanding and relationship with Indigenous peoples. (121) This needs to be integrated directly into healthcare professional training, especially for frontline workers. For example, to avoid stereotyping and discrimination healthcare professionals need to be aware of the diversity within Indigenous beliefs, practices, and traditions. (121) This means that all healthcare staff, especially frontline workers, need to be properly educated on the

historical and intergenerational trauma experienced by Indigenous peoples. I would expect all healthcare personal to go through an Indigenization process of their educational understandings of Canadian history. This means having at least the basic university level of Indigenous Studies introductory course (at the University of Saskatchewan it is Indigenous Studies 107.3: Introduction to Canadian Indigenous Studies). This course needs to be a pre-requisite to being a physician, nurse, healthcare administrative assistant, emergency medical technician, or police officer. Cultural safety workshops should be demanded for all healthcare professionals. (58)

Cultural humility is when people are open to learning and listening without judgement while self-reflecting on their own sociocultural positioning. For example, healthcare professionals frequently engaging with Indigenous communities by participating in cultural ceremonies like sweat lodges, pipe ceremonies, and smudges as part of their training before completing their course or certification. This is an important part of awareness training as well; since one can see the different cultural practices, histories, and beliefs of Indigenous peoples compared to their own cultural backgrounds. It allows the healthcare professional to realize that there is more than one approach to healing, and understanding that different perspective first-hand can be the mind-altering experience needed to truly change their understanding. I cannot stress this part of culturally training enough; it is absolutely essential. Although I do caution that healthcare professionals should do this as the last part of their training for they will get nothing out of this authentic experience if they do not fully understand the histories, traditions, and ceremonial significance if they are not educated well-enough beforehand.

Cultural competency are policies implemented to enhance cultural skills, such as behaviours and attitudes, that work effectively towards respecting the diversity of other people particularly those in a system, agency, or among professionals.(120,121) This does not mean we

have to become experts in cultures other than our own; however, it does mean that we have to reduce the number of assumptions we have towards other peoples.(120) For example, integrating appropriate materials developed by local Indigenous communities, such as pamphlets, banners, and artwork. (96) Some effective strategies for promoting breast health for Indigenous women are face-to-face interventions, culturally appropriate educational materials, and using traditional healing methods such as storytelling to enhance holistic healing practices. (35) This is essential since Indigenous patient comfort levels increase when healthcare organizations respect a patient's cultural beliefs by incorporating traditional medicines, ceremonies, and healers within the patient's treatment plan. (40,76,87) In traditional Indigenous cultures, healthcare is a partnership between the healer and the patient; this means that any move toward a more culturally competent healthcare system must include healthcare providers viewing themselves as healthcare partners with Indigenous patients and peoples. (50) For example, there should be an increase in the number of Indigenous peoples available as healthcare workers in health settings, such as Indigenous nurse aides. (58)

6.1.2 Systematic Challenges

"She goes, "Is the issue of the male doctor touching and examining your breasts the issue? Or is the issue that you don't want to be examined at all?" I said "The issue is the male doctor." I said, "I should have been told; a female doctor should have been here." That's my track record among my doctors and she goes, "Okay," so she left and she comes back and says, "We can have a woman doctor here in twenty five minutes if you want to wait." I said, "Great, let's wait," and so that's what I did, I waited. But I couldn't believe having to make that decision because nowhere on the forms does it say, "I want to be seen by a woman doctor," or something like that right? There's nowhere to check that off. It's an assumption made and for Aboriginal

women, it's not something we do, right? We go in a sweat lodge and cover up in a blanket, you know? We cover, cover, we're covering ourselves constantly, so yeah that was the big one that really scared me...- Quintan

Many structural issues related to hospital norms are relevant for Indigenous women who, in other studies, have found themselves in uncomfortable situations such as sharing rooms with men or having male healthcare staff; these instances were viewed as being culturally unsafe. (20) Feelings of shame and embarrassment are heightened for women who feel uncomfortable exposing themselves to the "white man's" medical gaze. (28,32) In another study on Indigenous women's breast cancer health, one participant mentioned that "...modesty was a barrier to screening, specifically regarding the use of male mammogram technicians, being uncovered during mammograms, and with touching themselves on the breast during the BSE [breast self-examination]". (35)^{p.381} For some Indigenous women, having a man who is not their partner touch their body violates cultural norms; as such, systematically including same-sex healthcare providers is important for delivering culturally appropriate care. (35) For example, Quintan, from our study, suggested one way to deal with the issue is to simply have a check-box on a patient's medical file that states a preference to be examined by a female doctor. This is a simple and important medical practice that could be applied in our healthcare system because for some Indigenous patients, especially women, exposure of the body is often associated with demeaning healthcare experiences or traumatic recollections of residential school. (60,87)

6.1.3 Elders and Nurse Navigators

"I think that [support from Aboriginal people in the healthcare system] would really, really help, especially for quiet, quieter people that you know, haven't been in the city or away from our environment, our own communities and families. I know that there's a system in the

hospital here and they send somebody to come and pray for you or talk to you in your own language, but there's not[hing like that] at the cancer clinic, you know, specifically for cancer patients to have Aboriginal stuff... if there was a dedicated team, Aboriginal team for the cancer patients, I think that would really help. It would have even helped me, you know. But it would have really helped those that don't have support." – Norma

The presence of friendly Indigenous staff within the healthcare system promotes patient feelings of comfort and familiarity in a mutual understanding through shared experiences of Indigenous ideology. (87) For example, some Indigenous patients found comfort and reassurance when they had a cultural umbrella to rely on in the foreign hospital environment. (74) It is also important to have an Indigenous aid in the healthcare setting for any translating that needs to be done. A participant in a study of Indigenous patients from Alberta expressed this as follows: "[w]hat I want is someone to be there was a translator because sometimes we [Indigenous peoples] don't understand especially high words in English when we are questioned by the staff. When we are scared or fearful we cannot just ask anyone for help because we don't know anyone here. It would be helpful to have someone in the hospital who speaks Cree". (58)^{p.E9} Many of the women also mentioned having someone who was Indigenous in the healthcare centre, just to talk to, would have been beneficial. Another suggestion was an Indigenous liaison or an Elder, someone from their culture, could help them come to terms with their diagnosis and treatment options.

"I think it would help but coming from an Elder who went through the same road, who went through the same experience of losing a breast...Somebody that you can relate to, and trust." – Ruth

Indigenous community members need to be recruited and trained as liaisons, and more culturally appropriate care needs to be developed in the healthcare system to provide proper care for this population. (78) As described by Indigenous patients, the advantage of having Elders to provide support is that they do so in a very individualized way that is relevant to that individual's specific situation. (76) Furthermore, Indigenous women value the presence of an Elder or Indigenous aide in the healthcare setting; (76) this leads to increased patient appreciation and communication. (93) Another study on Indigenous peoples' experiences in the healthcare system suggests that there is a desire to see Indigenous peoples available within the services they use. (96) Finally, if an Indigenous woman needs to be called back to the healthcare center for more treatment, or further investigation, an Indigenous aide could closely work with that patient to counteract any potential fears with the mainstream healthcare system. (36)

6.1.4 Indigenous Based Health Education Materials

“As your patients come from, like more isolated areas and where the Indigenous language is more and they live more traditionally I think those issues are something that have to be considered in that way, like my aunty and I sat around like they worked on a – a dictionary of medical terminology to trying to – so they could explain to patients that were come from – from the north you know.” - Tara

Increasing the visibility of Indigenous women as breast cancer survivors will help other Indigenous women pay closer attention to early warning signs of the disease; seeking medical care sooner is important for decreasing the mortality rates within this population. (31) As mentioned by Bronwyn Fredricks, “[i]f Indigenous women are not part of the design process they are reflected within the social, political and economic values by their absence. It is very clear the role that memory, representations, symbols and images have in showcasing who is of

value and who is not". (96)^{p.11} Research in Queensland found that Indigenous women with breast cancer felt that "...the mainstream materials were not always appropriate, did not catch the attention of Indigenous women, or were not seen as relevant to them". (96)^{p.4} One way for the healthcare system to implement decision-making materials that involved Indigenous women is to have them produced by Indigenous women. (107) This is because, "... the act of participating in the creation of health information... influences patients' experiences and has implications for our understanding of their role in their own healthcare management and information". (141)^{p.220} For example, "...by depicting a First Nations (sic) woman in the graphics, meetings attendees agreed that the material seems more relatable and appealing to a First Nations (sic) audience". (147)^{p.336} Culturally appropriate educational materials have been found effective at increasing mammography rates. (141)

Using eye-catching pamphlets and storytelling techniques in cancer screening are good ways to promote Indigenous women's health, especially health education that respects the depiction of female bodies and sexuality from an Indigenous perspective. (141) For example, "T-shirts, pens and buttons should be consistent with its message and capture the attention of different generations". (148,149)^{p.336} In a previous study, a local artist was hired to create the promotional imagery for Indigenous health education. (52)



Figure 6. 1: The Anishinaabek Cervical Cancer Screening Study⁶

⁶ Magajna B, Zehbe I. The Anishinaabek Cervical Cancer Screening Study – A Community Update Gathering Looking Back and Moving Forward: Findings from Reflective Sharing Circles EVALUATING PAST PRACTICES AND DEFINING AND PLANNING FOR FUTURE SUCCESS [Internet]. Lakehead University. 2016 [cited 2018

Educating Indigenous communities about the risks, screening practices, and treatment options with respect to breast cancer can perhaps best be done in the form of story-telling from survivors or family members who have personal experience with the disease. There is a transformative power of storytelling that is well documented within Indigenous cultures and Elders. (150)

Figure 6. 2: Turtle Logo for Anishinaabek Screening Study Cervical Cancer Screening⁷



Breast cancer screening and treatment options available in the patient's native language, specifically in audio and video format, would be beneficial as well; those who only speak their traditional Indigenous language are more likely to be illiterate, so written health material would be of no benefit. (88,117) Thus, another option for health education outreach would

be radio advertisements, especially in northern communities, around the importance of breast cancer screening, which could be broadcast in various Indigenous languages spoken in the area.

6.1.5 Traditional Medicines Used for Cancer

“...I didn't say anything to my chemo doctor [about taking traditional medicines] because every time I went and got checked he said, "Oh, there! The tumor; it's shrinking!" He

Feb 18]. p. 1. Available from: http://www.accsfn.com/uploads/1/4/1/6/14167096/sharing_circle_poster_-_march_3_2016_revised_5.pdf; pg. 1.

⁷ Zehbe I, Magajna B, Thunder Bay Regional Research Institute, Thunder Bay Regional Health Sciences Centre, Lakehead University, Canadian Institute for Health Information. Anishinaabek Cervical Cancer Screening Study: Community Update Report 2015 [Internet]. Thunder Bay, ON; 2015 [cited 2018 Feb 18]. Available from: https://www.accsfn.com/uploads/1/4/1/6/14167096/access_report_cih.pdf; pg. 23.

said, "This is how much it's shrunk already!" He's telling me like kind of looking at me eh? I said, "Oh, okay! That's good!" I'm thinking eh? But in the back of my mind and I'm thinking, "I wonder if I should tell him," I don't know but it was like, okay it's working. It's helping me. That's all that was in my mind. I'll keep doing it. You know? I'll keep drinking it [my teas]." - Stacey

Studies have found that Indigenous peoples need to have a strong belief or faith in a certain kind of medicine for it to work properly. (88) This belief makes it very important for some Indigenous peoples, who are diagnosed with cancer, to seek out their traditional medicines, either alone or along with their western treatments.

It would be very beneficial for the healthcare system to integrate Indigenous traditional medicines into the cancer treatment decision-making process. However, due to the minimal amount of information that exists in the literature to explain how the healthcare system integrates Indigenous traditional medicines into cancer treatment decision-making, further research could build on this concept to help guide those who want a traditional healing options during their cancer treatments. As mentioned in a previous study on Indigenous traditional healing and cancer, "[e]ncouraging native Indigenous peoples to seek assistance with their healthcare needs through ancient healing practices may help alleviate and minimize such disparities". (117)^{pp.22} In a previous study on treating cancer among Indigenous peoples, some participants expressed confusion around traditional medicines because they were unsure of the process of taking it, did not have access to it, or were unsure how it would interfere with their western cancer treatments. (117) Integrating traditional treatment options within the healthcare system, it has the potential to positively affect Indigenous populations' health outcomes. (121) It also has the potential to allow other cancer patients to choose these treatment options as well.

6.1.6 Ask

"[Some good advice would be]... more or less it's like you're supporting them, and it's good to ask them - like a lot of times their culture, you know? Like what are their beliefs? What's your culture's beliefs?... I would have wanted to be asked that, but my doctors never. That doctor I had, never asked me...: It probably would've made a big difference for me because it would've made me think what it is that I really need to do, you know, as a First Nations person." -Stacey

The literature suggests that even urban-residing Indigenous populations are often reluctant to reveal information about using traditional medicines with their healthcare provider. (132) However, having an open conversation about these things, might encourage Indigenous women to open up to their healthcare providers. Another important step in being culturally competent is accurately identifying the patient's values and beliefs so they can be provided with the best quality of care. According to Barry et al, "[p]atient involvement in decision-making adds substantial value". (40)^{pp.780} However, the difficulty in this situation is that healthcare providers are unclear about what a patient's ethnicity, traditions, and worldview might be. (76) Furthermore, scholars caution against ethnic matching for Indigenous health because it is not always feasible, "...nor does it reduce value conflicts or ensure that the interaction will be culturally sensitive". (40,121)^{pp.743} To minimize misunderstandings, such as stereotyping, healthcare professionals need to ask individual patients how they self-identify and, about their cultural beliefs and practices. (132)

The best way to determine the patient's preferences is to simply ask them. One of the ways this is done in practice is to have the physician ask, "[w]hat matters to you?" (74)^{pp.781} As some literature suggests nurses have also been encouraged to ask questions such as, "[t]ell me what I need to know about your culture in order to give you good nursing care". (151)^{pp.21} A

useful way to encourage patients to voice their fears around cancer, and therefore to increase the physician's ability to support the patient's decision, is to ask questions such as "Have you ever known anyone with breast cancer and what was the outcome?... Are there specific areas of your care or treatment options which you would like more information about?... Would you like me to recommend a treatment plan to assist in your decision-making?" (132)^{pp.185}

6.1.7 The Internet as a Source of Connecting

"I found groups online that we really want to talk to each other. It's a place for us even if I just want to rant and rave about the side effects I can do that.... I don't have to rant and rave to my family and put this burden on my family. We understand the side effects. We understand our treatments and how we feel." - Bernadette

Decision aids have been a great resource or tool used to properly inform patients about their treatment options. Decision aids can either be information delivered online, on paper, or on video. (107) Some participants have suggested using the internet to connect, gain knowledge, and create support groups online with other Indigenous women with breast cancer. Indeed, one in four internet users living with a chronic condition, such as cancer, report going online to find information about their disease. (152)

Although the online world is essentially an extension of our physical reality, meaning that cyberspace is still embedded within certain cultural, social, and material contexts, the internet still has the ability to transcend space and distance. (107) Social media can surpass educational achievement, level of access to care, as well as an individual's racial or ethnic status. (107) These are important factors when dealing with Indigenous women, especially those in rural/remote locations where it is more difficult to get these women together in one physical location. Online support also has the ability to address certain healthcare needs, such as support during unsocial

hours, as well as to provide an anonymous platform to express concerns in cases when people might feel embarrassed or nervous asking certain questions face-to-face. (153)

It is also important to remember the way that the internet can portray Indigenous women with breast cancer. A study by Alexandra Gibson, Christina Lee, and Shona Crabb looked at online media portrayal of Indigenous women with cancer and revealed further stigmatization.(153) This was done by select language which constructed non-western women as ignorant and holding beliefs that needed correction, presenting dominant western perspectives of breast cancer as correct, and having ambiguous supportive information on traditional Indigenous medicines. (150) Instead, the online portrayal of Indigenous women with breast cancer should be supportive of Indigenous ways of healing and focused on providing culturally appropriate support, such as contact information for Indigenous women who are cancer survivors, layman's terminology of medical jargon, descriptions of the different stages of breast cancer, translations of medical terminology into various Indigenous languages [in audio format because those who are very traditional are more likely to be illiterate so having written terminology will not be very useful], (150) and perhaps illustrations of breast cancer guidance and awareness by a local Indigenous artist. (152)

More research should be done in the area of online enhancement in this field to ensure that Indigenous women are accessing the information and resources they need to be well informed about breast cancer. Although online engagement can mobilize collective efforts and enhance individual identity, (20) further research would need to be done within Indigenous populations in Canada [especially those in rural/remote locations] to determine if this an effective strategy amongst this population. Considering the increasing usage of technology in our society today as well as the importance of reaching those living in rural/remote locations, this

might be a beneficial strategy, especially for youth who might be more inclined to use the internet as a source of knowledge.

6.2 Summary

Canada's health care system is currently dominated by the western scientific way of thinking and where Christianity plays a big role in the structural and spiritual aspects of the medical institution. Although shifts are now occurring, with medical facilities being more inclusive of other cultures, it is imperative that Indigenous women (and all ethnicities) are respected and not only allowed to practice their traditional healing techniques but also able to choose which medical treatments they want to have in their cancer treatment plan. It is important to use the strengths of both Indigenous culture and western medical systems to promote health.

(104) To illegitimize knowledge and problem-solving strategies that have evolved from Indigenous communities over hundreds of years and disallowing this knowledge to produce and exchange in our contemporary institutions, "...is not only hostile, but makes little economic and strategic sense." (28)^{pp.5} To move forward, Indigenous peoples and healthcare professionals need to work together to reconcile attitudes that have created barriers in healthcare reform. (55)

Indigenous women suggest being intimately involved in the decision-making process in relation to health education and policy changes would be meaningful to the Indigenous lives they will ultimately affect. (34) Modifying attitudes to increase early breast cancer diagnosis might be possible, because early stage breast cancer can be addressed by targeting cultural factors, rather than just socioeconomic ones (which can be difficult to change). (154) However, socioeconomic factors need to be addressed as well to truly improve breast cancer survival. (20,58)

Being culturally safe has been described by Indigenous peoples as being visible in the healthcare setting, treated as a human being, respected, and listened to. (155) Most of the women

stressed the importance of the healthcare system honouring Indigenous practices and beliefs during the decision-making process around cancer treatment. This included culturally appropriate ways of being educated about the disease, and having a connecting network set up in the healthcare setting so they are not forced to find one another for support.

6.3 Strengths

Transferability, unique insights, relationship building, community engagement and policy implementation are all strengths in this research project. Transferability is applicable because this research aligns with similar findings of Indigenous women with breast cancer in recent times in the same area. (15,43,75,150,156,157) Unique insights are an important part of qualitative research which cannot be found through quantitative findings alone. For example, knowing that Indigenous women are being diagnosed with breast cancer at a later stage in the disease does not tell us why this is occurring. Understanding how these women make decisions around cancer treatment show insight into this issue.

Relationship building and community engagement are extremely positive parts of this research project. Without being able to build trust and respect with members of the Indigenous community, stops the research right there. It is the participants who make the project a reality, as it is their lives that are being affected in very intimate ways. It takes great courage and vulnerability to share such sensitive aspects of their lives.

The ultimate goal then is to implement health policy changes, additional research, knowledge transfer, and cultural safety training at all levels of healthcare and other professions being front-line staff in healthcare settings. Health policy changes need to be addressed at the federal level with Health Canada to make choices around breast cancer treatment more equitable; this includes additional financial coverage for time of work, travel, and medical expenses

(included prostheses products and accessories). This enables lower income patients to actually make a choice on their preferred treatment type, instead of focusing on what they can choose based on their socioeconomic positioning. Additional research into Indigenous medicines used for cancer would be extremely beneficial for the healthcare system to understand which CAMs are appropriate and in which contexts so they can be prescribed with confidence by healthcare staff. Along with that notion, additional research on Indigenous nurse aides assisting Indigenous cancer patients as they make decisions about cancer treatments will shed more light on their level of participation when making these decisions. Theatrical plays written based on this research project's findings and composed by an Indigenous playwright from the University of Alberta, Ken Williams, will increase public knowledge about these issues. Implementing more cultural safety training for all healthcare professionals and front-line workers will help to build trust and understanding between western and Indigenous cultures. This will decrease the incidence of racism and discrimination against Indigenous peoples who are seeking medical care from the Canadian healthcare system.

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APPENDIX A: SUMMARY OF THE STUDY



UNIVERSITY OF SASKATCHEWAN

College of Medicine **Developing a Culturally Appropriate
Framework for Cancer Care Decision-making**

MEDICINE.USASK.CA

What is the goal of this research?

- We want to understand how individuals in your community make cancer related decisions.
- We want to understand how First Nations and *Métis* patients experience the healthcare system.
- We want to understand cancer, culture, health and healing from your perspective.
- We will use the information to help develop a model of healthcare that best serves First Nations and *Métis* people.

Who are we looking for?

- We are wanting to speak with First Nations, and *Métis* cancer survivors, or those currently dealing with cancer.

What would your role be as a participant?

- Should you choose to participate, a member from our research team will contact you to set up a time to be interviewed by Dr. Gary Groot and a First Nations member of our team. This meeting should last approximately one hour.
- With your consent, this interview will be audio recorded to ensure we accurately represent your statements.
- In this meeting, we hope you can share information with us about your cancer journey and experiences with the healthcare system.

What we promise you:

- Our research team will listen to your story.
- Everything you choose to share with us will remain confidential.
- If you wish, we will share our results with you following the completion of the study.

Why is this research important?

- We know that involving patients and honouring their values in decision-making can improve patient outcomes, yet we have a lack of understanding of First Nations and *Métis* decision-making processes. Understanding the values and preferences of First Nations and *Métis* people will help us to form a better understanding of their needs.

Funding

- This project is currently funded by a Saskatchewan Health Research Foundation grant

Questions?

If you have any questions, please feel free to contact our research team:

- Dr. Gary Groot: gary.groot@usask.ca or 306-966-1670
- Or Dr. Rose Roberts: rose.roberts64@gmail.com

APPENDIX B: INTERVIEW SCRIPT AND PROMPTS

Interview Script and Prompts

Our study is about First Nations and Metis experiences with cancer. We are interested in hearing about your experiences.

- 1) Can you tell me about your cancer?

Prompts:

- a) When were you first diagnosed?
 - b) How old were you then?
 - c) What was your experience?
 - a. With the doctor
 - b. With others
 - d) What was your health like before you were diagnosed with breast cancer?
 - e) What treatments have you had for cancer? (western medicine and/or other therapies)
-
- 2) How did you decide what treatments to take?

Prompts:

 - a) What role did doctors, nurses and other health providers play in your treatment decisions?
 - b) What role did your family and friends play in your treatment decisions?
 - c) What role did your community play in your treatment decisions?
 - 3) What role has culture played in the decisions you have made about your treatments?
 - 4) What role has western medicine played in the decisions you have made about your treatments?
 - 5) Is there anything else that you would like to share about your experiences with cancer?
 - 6) Is there anything else that you would like to share about your experiences with treatment or healthcare providers?

APPENDIX C: LETTER OF ACCEPTANCE FOR ETHICAL APPROVAL



Dr. Gary Groot
College of Medicine
University of Saskatchewan
Saskatoon, SK
S7N 5E5

April 25, 2016

RE: 2016-075: Engaging with Elders: Development of a Culturally Appropriate Framework for Aboriginal Women with Breast Cancer in Healthcare Decision-making

Dear Dr. Groot,

Your application for research ethics review has undergone a harmonized review by the University of Regina and the University of Saskatchewan. In accordance with the Research Ethics Review Reciprocity Agreement signed by the University of Saskatchewan, the University of Regina, and the Regina Qu'Appelle Health Region, the University of Regina REB accepts the Certificate of Approval issued by the University of Saskatchewan REB. **This letter is issued to you in lieu of a Certificate of Approval by the University of Regina REB.** This letter permits you to conduct research activities as approved by the University of Saskatchewan REB, provided that you maintain a valid and up-to-date Certificate of Approval.

All continuing ethics review will be conducted by the University of Saskatchewan REB. The University of Saskatchewan is authorized to share all communications pertaining to this file with the University of Regina REB at their discretion. The University of Regina REB may provide input into continuing ethical review activities, as agreed upon by both REBs.

The University of Regina REB reserves the right to revoke the privileges described in this letter at any time in order to conduct their own independent research ethics review of your project. Such a decision would be communicated to you and the University of Saskatchewan REB in writing.

Best wishes for your continuing research endeavours. Sincerely,

Dr. Larena Hoeber
Chair, Research Ethics Board

research.ethics@uregina.ca Phone: (306) 585-4775 Fax: (306) 585-4893

Letter of Acceptance



UNIVERSITY OF SASKATCHEWAN

College of Medicine

Participant Consent Form

DEPARTMENT OF COMMUNITY
HEALTH AND EPIDEMIOLOGY
MEDICINE.USASK.CA

You are invited to participate in a research study entitled:

Development of a Culturally Appropriate Framework for Aboriginal Women with Breast Cancer in Healthcare Decision-making

Researcher:

Dr. Gary Groot, Associate Professor
Department of Community Health and Epidemiology
College of Medicine, University of Saskatchewan
Ph: 306-966-1670 Email: gary.groot@usask.ca

Co-Investigators:

Rose Roberts, Sessional Lecturer
Department of Women and Gender Studies
College of Arts and Science, University of Saskatchewan
Ph: 306-370-7815 Email: rose.roberts64@gmail.com

Tania Lafontaine, HR Consultant
Saskatoon Health Region
First Nations and Métis Health Services -Representative Workforce
Ph: 306-625-3985 Email: tania.lafontaine@saskatoonhealthregion.ca

Lorna Arcand, Patient Advisor
Email: lilgeneral4@gmail.com

Purpose(s) and Objective(s) of the Research:

Qualitative interviews will be carried out with the purpose of:

- Recording and understanding the experiences of First Nations and Métis cancer patients and survivors in their words.
- Understanding cancer, culture, health and healing from an indigenous perspective.
- Integrating knowledge gained into a patient-centered model of care that best serves First Nations and Métis people.

Procedures:

- As a participant in this study, you will be interviewed by Dr. Gary Groot and an Aboriginal member of our research team about your experience with cancer and the healthcare system. We expect the interview to take about 1 hour.

- With your permission, I will video record and take notes during the interview. The recording is to accurately record the information you provide, and will be used for transcription purposes. If you choose not to be videotaped, I will take notes instead.
- If you agree to being videotaped but feel uncomfortable at any time during the interview, I can turn off the recorder at your request. Or if you don't wish to continue, you can stop the interview at any time and information collected will be destroyed.

Funded by:

- Saskatchewan Health Research Foundation – Collaborative Innovation Development Grants

Potential Risks:

- Although there are no anticipated risks to you by participating in this research, being asked to talk about your personal experiences with health and healing may be emotionally upsetting. If, at any time, you feel uncomfortable in during the interview, you have the right to decline to answer any question or to end the interview.
- If necessary, we can provide referrals for counseling and other services.

Potential Benefits:

- There is no direct benefit to you from taking part in this study. It is hoped that the research will provide the ground work to develop a culturally competent and sensitive patient-centered model for healthcare professionals that will best serve First Nations or Métispatients.

Compensation:

- Participants will be compensated \$300.

Confidentiality:

- Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used.
- **Storage of Data:**
 - Electronic data will be stored on a secure server on password protected computers at the University of Saskatchewan. Any paper documents will be stored in a locked filing cabinet at the University of Saskatchewan.
 - Records will be retained in this way up to 5 years after the study is completed. All paper documents will be shredded, and electronic files will be deleted after 5 years.

Right to Withdraw:

- Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.
- Whether you choose to participate or not will have no effect on your healthcare or how you will be treated.
- Should you wish to withdraw from the study at any time, you may do so by contacting any of the study investigators at the top of page 1. Your right to withdraw data from the study will apply until results have been disseminated. After this time, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

Follow up:

- If you have further questions once the interview is completed, you are encouraged to contact the researchers using the contact information at the top of page 1.
- Where necessary and possible, researchers would like to re-contact participants after all interviews are completed to verify findings and our interpretation.

Questions or Concerns:

- If you have any questions about this research, please feel free to contact the researchers using the contact information at the top of page 1.
- This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Consent:

SIGNED CONSENT

Your signature below indicates that you have read and understand the description provided;

- I have had an opportunity to ask questions and my/our questions have been answered.
- I consent to participate in the research project.
- A copy of this Consent Form has been given to me for my records.

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
<i>Researcher's Signature</i>	<i>Date</i>	

A copy of this consent will be left with you, and a copy will be taken by the researcher.

ORAL CONSENT

Oral Consent: If on the other hand the consent has been obtained orally, this should be recorded. For example, the Consent Form dated, and signed by the researcher(s) indicating that “I read and explained this Consent Form to the participant before receiving the participant’s consent, and the participant had knowledge of its contents and appeared to understand it.” In addition, consent may be audio or videotaped.

<i>Name of Participant</i>	<i>Researcher's Signature</i>	<i>Date</i>
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CURRICULUM VITAE
For
Chanda C. Hetzel
2018

1. CONTACT INFORMATION:

Email: chanda.hetzel@usask.ca

2. ACADEMIC CREDENTIALS

2015 – 2018 **M.A. Student, Department of Sociology**
University of Saskatchewan

2010 - 2015 **B.A. Honours, Department of Sociology**
University of Saskatchewan

3. AREAS OF SPECIALIZATION, TEACHING AND RESEARCH INTERESTS:

Health; Policy; Gender; Language; Race/Ethnicity; Transnationalism; Media Studies; and Social Justice

4. HONOURS (AWARDS, FELLOWSHIPS, PRIZES):

2015 – 2017 **Saskatchewan Innovation Grant Scholarship**
University of Saskatchewan
Amount Awarded: \$40 000

2015 **Roy Atkinson Scholarship**
University of Saskatchewan
Amount Awarded: \$900.00

2013 **Service and Justice Award**
St. Thomas More
Amount Awarded: \$500.00

5. RESEARCH POSITIONS:

Jan. 2017 – Aug. 2017 **Research Assistant**
Title: *Emerging Adulthood: Cohabiting Patterns in Canada*
PI: Dr. Laura Wright, Sociology Department, University of Saskatchewan, literature review, quantitative research analysis.

- Sept. 2015 - April 2016 **Research Assistant**
 Title: *Early Addictions Recovery Experiences from Urban Indigenous Youth*
 PI: Dr. John Hansen, Sociology Department, University of Saskatchewan, ethics, data gathering, qualitative research analysis, report and academic writing.
- April 2015 - Dec. 2015 **Research Assistant**
 Title: *Bullying in the Workplace*
 PI: Dr. Elizabeth Quinlan, Sociology Department, University of Saskatchewan, literature review, editing, filing, participant recruitment, data gathering.
- 6. PREVIOUS TEACHING AND RELATED EMPLOYMENT:**
- Sept. 2016 – April 2017 **TEACHING ASSISTANT**
 Classes: Sociology 212.2 & 212.4: Criminology
 Professor: Dr. Carolyn Brooks, Sociology Department, University of Saskatchewan, guest lecturer, marking.
- Jan. 2016 - April 2016 **TEACHING ASSISTANT**
 Classes: Psychology 222: Personality & Psychology 223: Abnormal Psychology
 Professor: Dr. Tracey Carr, Psychology Department, St. Thomas More, marking.
- Jan 28, 2016 **GUEST LECTURER**
 Class: Sociology 841: Methodology
 Professor: Dr. Parvinder Hira-Friesen, Sociology Department, University of Saskatchewan, guest lecturer.
- 7. MEMBERSHIP:**
- Sept. 2016 – Sept. 2017 **PRESIDENT**
 Organization: Sociology Graduate Students' Association (SGSA), University of Saskatchewan
 Tasks: provide leadership, organizational skills, and vision; gauge the needs and interests of sociology graduate students; call executive and general meetings; sit on the appropriate committees.
- Sept. 2014 – April 2015 **VICE PRESIDENT**
 Organization: Sociology Undergraduate Students' Association (SUSA), University of Saskatchewan
 Tasks: communicate between students, staff, and faculty; coordinate meetings; engage with campus community; stabilize operations of the organization.

8. CHAPTER PART IN BOOKS:

Exploring Sociology: A Canadian Perspective, Third Edition by Bruce Ravelli and Michelle Webber. Copyright @ 2016 by Pearson Learning Solutions

9. PRESENTATIONS AT CONFERENCES:

Hetzel, Chanda. "*Decision-making Process for Indigenous Women with Breast Cancer.*" Poster Presentation for the Building Reconciliation Forum at the University of Saskatchewan, March 7, 2017, Saskatoon, SK.

Hetzel, Chanda. "*Decision-making Process for Indigenous Women with Breast Cancer.*" Department of Surgery Faculty Research Day at the Rependa Centre Auditorium in Saskatoon City Hospital, April 4, 2017, Saskatoon, SK.

10. PAPERS IN REFERRED JOURNALS:

Hansen, J. G., & **Hetzel, C. C.** (2018). Exploring the Addiction Recovery Experiences of Urban Indigenous Youth and Non-Indigenous Youth Who Utilize the Services of The Saskatoon Community Arts Program. *Aboriginal Policy Studies*, 7(1), 84-102.
doi: <https://doi.org/10.5663/aps.v7i1.28525>