

# Rural Women's Perspectives on Cancer Care in Southern Saskatchewan

A Thesis Submitted to the College of Graduate and Postdoctoral Studies

In Partial Fulfillment of the Requirements for the Degree of Master of Nursing

In the College of Nursing

University of Saskatchewan

By

Sarah Taylor

© Copyright Sarah Taylor, May 2021. All rights reserved.

Unless otherwise noted, copyright of the material in this thesis belongs to the author.

## PERMISSION TO USE

In presenting this thesis/dissertation in partial fulfillment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this thesis/dissertation in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis/dissertation work or, in their absence, by the Dean of the College of Nursing in which my thesis work was done. It is understood that any copying or publication or use of this thesis/dissertation or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis/dissertation.

Requests for permission to copy or to make other use of material in this thesis in whole or part should be addressed to:

Dr. Pammla Petrucka  
College of Nursing  
University of Saskatchewan  
Health Science Building – 1A10, Box 6  
107 Wiggins Road  
Saskatoon, Saskatchewan S7N 5E5  
Canada

OR

Dean  
College of Graduate and Postdoctoral Studies  
University of Saskatchewan  
116 Thorvaldson Building, 110 Science Place  
Saskatoon, Saskatchewan S7N 5C9  
Canada

## ABSTRACT

One in two Canadians will be diagnosed with cancer in their lifetime. A cancer diagnosis requires supportive care during diagnosis, treatment, follow up and palliative care. Those living in rural areas in Canada experience additional burdens in meeting supportive care needs. The purpose of this study was to explore the experiences of women who had been diagnosed with cancer living in a rural area, related to met and unmet supportive care needs. The intent is to give a voice to rural women with cancer and to inform oncology programming that is specific to rural residents. The study objectives were to understand the benefits and burdens to meeting supportive care needs of women living in rural areas with cancer and to identify ways that the rural healthcare system can meet these needs. The qualitative method, Interpretive Description, was used for this study. Data was collected by interviews with rural women who had been diagnosed with cancer within the last five years or who were still undergoing treatment. Data analysis was done concurrently with data collection, which is congruent with Interpretive Description.

The findings of this study center around four themes and 14 sub-themes. The themes were “Feelings – From normal life to chaos”; ”Self-efficacy and resiliency – Get up and get going ‘cause there’s things to do”; “Timing – And then the whole month was just waiting”; and “Access – For the most part you just drive”. Generally, the rural women were often found to be in deficit positions with respect to select service providers, health information, and logistical issues, but they remained thankful, positive, and engaged in their care. Recommendations for this study included the use of social media and online services for support and informational needs, and the use of a nurse navigator who is specific to rural oncology, as well as recommendations for nursing practice, policy, and future research.

## **ACKNOWLEDGEMENTS**

I am grateful to many people who helped in the completion of this project. First, to the women who participated in this research, for sharing your stories so honestly. Thank you for trusting me to tell your story. I would like to thank my thesis supervisor and my committee members for your support and patience through this process, your contributions helped me grow professionally and academically. I would like to acknowledge the support from my husband and family. You have been a source of strength through the many stages of this project.

This thesis is written in memory of my mom, Patricia, the reason I am so passionate about the stories and experiences of rural women and improving rural cancer care.

## Table of Contents

<b>PERMISSION TO USE.....</b>	<b>i</b>
<b>ABSTRACT.....</b>	<b>ii</b>
<b>ACKNOWLEDGEMENTS .....</b>	<b>iii</b>
<b>CHAPTER ONE .....</b>	<b>1</b>
<b>1.1 Introduction.....</b>	<b>1</b>
<b>1.2 Background.....</b>	<b>1</b>
<b>1.3 Significance to Nursing .....</b>	<b>5</b>
<b>1.4 Problem Statement.....</b>	<b>7</b>
<b>1.5 Research Purpose and Objectives .....</b>	<b>7</b>
<b>1.6 Research Question .....</b>	<b>8</b>
<b>1.7 Summary.....</b>	<b>8</b>
<b>CHAPTER TWO .....</b>	<b>9</b>
<b>2.1 Overview .....</b>	<b>9</b>
<b>2.2 Physical Domain.....</b>	<b>9</b>
<b>2.3 Informational Domain .....</b>	<b>10</b>
<b>2.4 Social Domain.....</b>	<b>11</b>
<b>2.5 Practical Domain.....</b>	<b>11</b>
<b>2.6 Emotional and Psychological Domains .....</b>	<b>14</b>
<b>2.7 Spiritual Domain.....</b>	<b>16</b>

2.8 Summary.....	16
<b>CHAPTER THREE .....</b>	<b>19</b>
3.1 Overview .....	19
3.2 Interpretive Description .....	19
3.2.1 <i>Sampling</i> .....	21
3.2.2 <i>Dealing with data collection and data analysis</i> .....	22
3.3 Situating Self in the Research Role .....	23
3.3.1 <i>Tracking reflections</i> .....	23
3.3.2 <i>Learning not to lead</i> .....	23
3.3.3 <i>Disclosing the discipline</i> .....	24
3.3.4 <i>Stepping out of the role</i> .....	24
3.3.5 <i>Revealing and Concealing</i> .....	24
3.3.6 <i>Negotiating informed consent</i> .....	25
3.3.7 <i>Finding your tongue</i> .....	25
3.3.8 <i>Constraining your influence</i> .....	26
3.4 Situating self in the setting .....	26
3.5 Data Collection .....	28
3.5.1 <i>Access and confidentiality</i> .....	28
3.5.2 <i>Interviewing</i> .....	28
3.5.3 <i>Managing and protecting data</i> .....	30

3.5.4 <i>Sorting and organization</i> .....	30
3.6 Data Analysis .....	30
3.7 Enhancing Credibility .....	31
3.8 Ethical Approval .....	33
3.9 Chapter Summary .....	34
<b>CHAPTER FOUR</b> .....	35
4.1 Overview .....	35
4.2 Feelings: “From normal life to chaos” .....	35
4.2.1 <i>Anxiety and worry</i> .....	35
4.2.2 <i>Loneliness</i> .....	36
4.2.3 <i>Humour</i> .....	37
4.2.4 <i>Gratitude and hope</i> .....	37
4.3 Self-Efficacy and Resiliency: “Get up and get going 'cause there’s things to do” .....	38
4.3.1 <i>Advocating for better care</i> .....	38
4.3.2 <i>“Doing what has to be done”</i> .....	39
4.3.3 <i>Concern for others</i> .....	40
4.4 Timing: “And then the whole month was just waiting” .....	41
4.4.1 <i>Timing of information</i> .....	41
4.4.2 <i>Waiting for services</i> .....	42
4.5 Access: “For the most part, you just drive” .....	43

4.5.1 <i>Travel</i> .....	43
4.5.2 <i>Travel alternatives</i> .....	46
4.5.3 <i>Access to information</i> .....	48
4.5.4 <i>Access to support</i> .....	49
4.5.5 <i>Access to services</i> .....	52
4.6 <b>Summary</b> .....	54
<b>CHAPTER FIVE</b> .....	56
5.1 <b>Overview</b> .....	56
5.2 <b>Feelings during the Cancer Continuum</b> .....	56
5.3 <b>Resiliency</b> .....	58
5.4 <b>Access</b> .....	59
5.4.1 <i>Social media</i> .....	61
5.5 <b>Information Needs</b> .....	63
<b>CHAPTER SIX</b> .....	64
6.1 <b>Overview</b> .....	64
6.2 <b>Implications for Nursing Practice</b> .....	64
6.3 <b>Implications for Nursing Research</b> .....	65
6.4 <b>Implications for Nursing Education</b> .....	65
6.5 <b>Implications for Policy and Administration</b> .....	66
6.6 <b>Nurse Navigators</b> .....	66



6.7 Meeting Supportive Care Needs Online.....	67
<b>CHAPTER SEVEN.....</b>	<b>69</b>
7.1 Overview .....	69
7.2 Limitations and Strengths .....	69
7.3 Knowledge Translation.....	70
7.4 Conclusions .....	71
<b>REFERENCES.....</b>	<b>72</b>
<b>Appendix A: Recruitment Poster .....</b>	<b>88</b>
<b>Appendix B: Consent Form Consent Form: Rural People’s Perspectives on Cancer Care in South Eastern Saskatchewan .....</b>	<b>89</b>
<b>Appendix C: Interview Guide.....</b>	<b>92</b>

## **CHAPTER ONE**

### **Introduction and Background**

#### **1.1 Introduction**

According to the Canadian Cancer Statistics Advisory Committee (2019), one in two Canadians will be diagnosed with cancer in their lifetime, and one in four Canadians will die from it. Cancer is the leading cause of death in Canada. Lung, breast, colorectal, and prostate cancer were projected to make up almost half of all new cancer cases in 2020 (Canadian Cancer Society, 2020). Age standardized incidence and death rates are decreasing, showing that prevention and treatment strategies are working. However, total cases and deaths are expected to rise due to a large, aging population. Cancer deaths have decreased by more than 35% in males and 20% in females since 1988. Five-year survival rates have increased from 55% in the 1990s to 63% in 2019 (Brenner et al., 2020; Canadian Cancer Statistic Advisory Committee, 2019).

Saskatchewan is expected to have 6,000 new cancer cases and 2,450 deaths in 2019 (Brenner et al., 2020). The high number of cancer cases expected in Canada means that many people will require supportive care before, during, and after their cancer diagnosis. Butow et al. (2012) define supportive care as “care that helps a person with cancer and their family cope with cancer and its treatment, from pre-diagnosis through the process of diagnosis and treatment to cure, continuing illness or death into bereavement” (p. 2).

#### **1.2 Background**

Those living in rural areas experience unmet needs, with additional burdens related to travel and access (Loughery & Woodgate, 2015). There are many different definitions of rural in the research literature which leads to a range from 19% to 30% of Canadians said to be living in rural areas (Kulig & Williams, 2012). Census rural “refers to the population living outside

settlements of 1000 or more inhabitants and with a population density of 400 or more inhabitants per square kilometer” (Kulig & Williams, p. 9). The census rural definition will be used for this study. Predominantly rural regions refer to areas where at least 50 percent of the population live in a community with a population density of fewer than 150 persons per square kilometer (Kulig & Williams). This lack of clarity and consistency may lead to the complex context of rural living not being reflected or fully embraced. Many rural health researchers acknowledge that definitions of rurality should consider social characteristics, descriptive features and rural residents’ own definitions of rural in order to encourage a more holistic approach to rural health research (Kulig & Williams, p. 7). For example, Rural and Small Town (RST) refers to “individuals in towns or municipalities outside the commuting zones of larger urban centres (with 10 000 or more population)” (Kulig & Williams, p. 9). The RST definition will be used for the purposes of this study as it emphasizes being outside commuting zones of large urban centers as a feature of rurality. By selecting this definition, we hope to make our results more comparable across research, practice, and theory.

Several studies have examined the differences in health between rural and urban Canadians and have generally found that those who live in rural communities present with poorer health and lower survival than their urban counterparts (Canadian Institute of Health Information [CIHI], 2018; [CIHI], 2006; Herbert, 2007; Pampalon et al., 2010; Sibley & Weinger, 2011). Sibley & Weiner (2011) used the Canadian Community Health Survey, conducted by Statistics Canada, to measure health care access and utilization of urban and rural Canadians across the continuum. This study used Metropolitan Influence Zones when describing rural populations. The MIZ are categorized according to the percentage of residents who commute to larger urban centres with strong MIZ having 30% or more commuting, moderate

MIZ having 5 to 29 % commuting, and weak MIZ having less than 5% commuting (CIHI, 2006). The researchers adjusted for other determinants using the Andersen's Health Behaviour Model and found that the most rural (those living in no or a weak MIZ) were the least likely to have had an influenza shot, indicating a lack of high-quality primary care; least likely to use specialists services; and the least likely to have a regular medical doctor. Rural residents were also less likely to report unmet care needs. The authors suggest rather than this being that their health care needs are being met, it is due to lower expectations of the health care system. This study suggests that even after other determinants are accounted for, an inequity in access to health care remains for rural residents in Canada.

The CIHI (2018) found that rural residents often face difficulties when accessing healthcare, have higher mortality rates, and report their health to be lower. The report suggests that, more specifically, travel distance when receiving healthcare adds to the barriers to care and that the burden of travel should be investigated in the context of health care access. The CIHI (2006) examined differences between rural and urban Canadians' socio-demographic and economic status, and health and health behaviors, within the context of the RST definition of rural. The report found that, in general, rural Canadians face disadvantages in terms of their health and health care. According to the report, life expectancy in both men and women is lower in rural areas. Cancer incidence and mortality rates vary for individuals living in census metropolitan areas (CMA) and surrounding areas. Men and women living in strong MIZ had the lowest incidence of cancer. Women aged 20-44 living in moderate to weak MIZ areas had a significantly higher rate of cancer than more urban areas (CIHI, 2006). Cervical cancer rates were significantly higher in the two most rural MIZ categories. Lip cancer in men showed increasing rates from urban to rural, which was the only cancer to show this trend. For mortality

rates, most results were not statistically significant when comparing rural versus urban cancer mortality rates (CIHI, 2006). Higher mortality rates were found in men aged 45 to 64 that were living in moderate MIZ and no MIZ than other zones (CIHI, 2006). Overall, men over the age of 65 living in rural areas had higher mortality rates than those living in urban areas (CIHI, 2006). In screening, women aged 50-69 living in moderate and weak MIZ areas were less likely to have mammogram screening than their urban counterparts. Men living in more rural areas were less likely to have routine PSA (prostate specific antigen) blood testing done (CIHI, 2006)

Living in a rural area adds another dimension to the care needs of those with a cancer diagnosis. Rural individuals with cancer report similar care needs to their urban counterparts; however, the burden of travel, receiving treatment away from home, and lack of resources, both human and material, often leads to more unmet care needs (Loughery & Woodgate, 2015). Psychological needs are often unmet due to the need to travel to the physical location of counselling services. Rural dwellers with cancer report difficulty in coping with emotions due to lack of anonymity in their rural community (Fuchsia Howard et al., 2014). Information needs for rural residents with cancer differ from their urban counterparts. Before and during treatment, information given before leaving home is important to ease anxiety for patients and their families (Butow et al., 2012). After treatment and during follow-up, information on healthy living may not be relevant for rural residents, depending on access to facilities and programs in the rural communities where they reside. Follow-up care for rural patients after diagnosis and treatment often falls to general practitioners. In one study, patients in some rural communities felt that their practitioner did not have enough cancer specific knowledge and that there was lack of coordination with specialists (Fuchsia et al., 2014) which was not experienced by urban patients.

The physical side effects of cancer treatment, such as pain, nausea, and fatigue, can be

distressing for any person receiving treatment. For rural individuals, the burden of travel negatively impacts the control of these symptoms and can cause anxiety (Lockie, et al., 2010; Loughery & Woodgate, 2015). Rural individuals who had to travel for palliative care noted pain as a major consideration. Pain medications are strategically taken in order to ensure coverage while commuting. Fatigue is also a common unmet need in palliative patients. Rural patients suffering from fatigue also planned trips for care, which include transportation, accommodations, and arranging for things to be taken care of at home while they are away, a burden that differs from their urban counterparts (Pesut et al., 2010).

Although the burden of travel and less resources may negatively impact the experience of someone living with cancer in a rural area, there are many benefits to rural dwelling. For many rural residents, rural living provides a sense of belonging and connecting with the physical space provides a positive impact on peoples' lives (Kulig & Williams, 2012). Other benefits of rural living include autonomy in day to day living and feeling supported by members of the community (Duggleby et al., 2011; Reid-Arndt & Cox, 2010).

The experiences of the individual living with cancer and their perceptions on their care needs through the cancer care continuum are very important. There is a need to develop a better understanding of these perceptions and experiences if health care professionals wish to improve supportive care for rural residents living with cancer (Fitch et al., 2009).

### **1.3 Significance to Nursing**

The role of the nurse in rural oncology care is diverse. Nurses in rural areas working with those who have been diagnosed with cancer are in an excellent position to assist with meeting supportive care needs, by providing information in a timely and appropriate way, and implementing interventions to reduce barriers to screening, diagnosis and treatment. These

nurses often understand the challenges and benefits of living in rural areas (Fitch et al., 2009; Hook et al., 2012; Loughery & Woodgate, 2015). Goodridge & Duggleby (2010) conducted focus groups and in-depth interviews with 44 nurses to explore palliative care in rural areas. The nurses expressed that a lack of human resources, inadequate education, ineffective communication between rural and urban care providers, and lack of physical supplies in the rural setting negatively impacted care.

There is a growing amount of evidence on the benefits of nurse navigators in the oncology setting. The Canadian Association of Nurses in Oncology (CANO) recognizes the importance of nurse navigators in improving outcomes for cancer patients. According to the CANO (2020) position statement “Patient navigators focus on understanding the unique barriers to care experienced by their patient and then work to help the patient overcome these barriers” (p. 1). Cancer patients have expressed overall higher satisfaction with their cancer experience when they had access to a nurse navigator, especially regarding emotional support. These findings are similar in all types of cancer (Loiselle et al, 2020). Other benefits in the research supporting the use of nurse navigators includes lower distress scores reported by inpatient oncology patients and improved communication between care providers, (Case, 2011; Swanson & Koch, 2010). Specific to rural care, Pesut et al. (2017) found that the use of nurse navigators in the rural palliative care setting was effective in meeting the needs of rural patients and their families. The patients and their families reported high satisfaction with the service and felt that the patient centered approach of the nurse in these positions benefited them in all domains; informational, psychosocial, and practical. Similarly, rural breast cancer patients in another study who had access to a nurse navigator reported that their educational and emotional needs were met by this service (Purtzer et al., 2012).

## **1.4 Problem Statement**

Individuals living in rural areas with a cancer diagnoses face unique burdens to meeting their care needs that their urban counterparts may not. Rural individuals report in much of the literature that their care needs are not being met in many areas along the cancer care continuum. In order to make recommendations and develop strategies to address unmet care needs of rural individuals with cancer, an increased understanding of the perceptions and experiences of these individuals is needed (Loughery & Woodgate, 2015).

## **1.5 Research Purpose and Objectives**

The purpose of this study was to explore the experiences and perceptions of women living with cancer and residing in rural areas in Southern Saskatchewan, according to the census rural definition, regarding met and unmet care needs. Southern Saskatchewan was the focus of this study as recruitment was taking place at the Allan Blair Cancer Centre, which is where most rural cancer patients living in Southern Saskatchewan access oncology care. The first objective of the study was to develop an understanding of the burdens and barriers to supportive care that women living in rural areas face, as well as how living in a rural area meets the needs of women with cancer. The second objective of the study was to identify what can be done within the rural health care system to meet the supportive care needs of these women in their rural dwelling. This research will potentially increase understanding of how rurality can impact cancer care. This study will contribute to the current literature on rural health and rural oncology care from a qualitative, patient focused, lens. The findings may have implications for rural health policy and future programming in cancer services in rural areas. It will also help rural nurses to understand the supportive care needs of their patients and ways to address them.



## **1.6 Research Question**

What are the perceptions of women living with a cancer diagnosis in rural Southern Saskatchewan regarding their met and unmet care needs?

## **1.7 Summary**

The large number of cancer cases expected in Canada will require those diagnosed to have access to supportive care through their cancer journey. Living in rural areas can mean these needs are unmet due to barriers specific to rural living. However, the many benefits of rural living should not be overlooked. Barriers to care and the role of the nurse as it relates to rural oncology care were discussed in this chapter. The many definitions of rural were also explained. This study aims to add to the literature on the rural cancer experience.

## **CHAPTER TWO**

### **The Literature Review**

#### **2.1 Overview**

This chapter provides an overview of the literature and significance of the research problem. The Supportive Care Framework for Cancer Care developed by Fitch and colleagues (2009) was used to organize the literature review, as well as guide the formation of interview questions for the study. This framework provides a multi-domain perspective to assist health care professionals in understanding the supportive care needs of their patients. These domains include physical, informational, social, practical, psychological/ emotional, and spiritual. A brief description is provided under each domain. Humans have more than just physical needs and they develop skills to meet their needs throughout their life. When a situation, such as cancer arises, some people find that the skills they have been using to meet their needs are no longer effective and they may have to find new information or learn new skills to try to meet their changing needs. If these needs remain unmet, individuals may feel distress. Cognitive appraisal is how a person thinks about an event or situation and then judges its effect on his/her health or well-being. Individuals use personal perspectives and beliefs to evaluate these situations and then emotional responses, followed by behavioural responses, emerge. If a person feels there is nothing they can do or change about the situation, they may feel emotionally distressed. Coping is what an individual does to manage a situation and the emotions that accompany it. Adjustment depends on many factors and can be associated with growth and development (Fitch et al., 2009)

#### **2.2 Physical Domain**

The physical domain addresses the physical needs of an individual to live comfortably, enabling them to carry out day to day functions (Fitch et al., 2009; Loughery & Woodgate, 2015). Symptom management is an ongoing concern throughout treatment and palliative care for

many cancer patients. Low energy and pain are noted in the literature as being unmet needs for many cancer patients at different stages of their cancer trajectory. Fatigue is a common unmet need in many different types of cancer. Hall et al. (2013) found that feeling tired was the most frequently reported unmet need in both Australian and Canadian hematological cancer survivors. Fitch & Steele (2010) found that lack of energy is the most frequently self-reported unmet need in lung cancer patients. Rural residents who must travel for treatment may experience a worsening in fatigue, as well as other symptoms such as pain, burning from radiation, or nausea from chemotherapy (Butow et al., 2012; Lougherty & Woodgate, 2015).

### **2.3 Informational Domain**

The informational domain addresses the need for information to assist with decision making, to develop new skills to cope, and to reduce psychological distress (Fitch et al., 2009; Loughery & Woodgate, 2015). A scoping review by Fletcher et al. (2017) showed that meeting informational needs of rural individuals with cancer throughout their cancer care experience decreases anxiety and fear. Loughery and Woodgate (2015) found that rural individuals facing a cancer diagnosis face challenges in accessing health care services across the continuum in their communities.

Treatment-related information needs make up the highest proportion of information needs (Fletcher et al., 2017). Written information, given in a timely manner, preferably before leaving home and in the right context, was found to be the most helpful for rural individuals travelling for cancer. Often, information given on side effects and supportive care services was given too late treatment (Butow et al., 2012; Gray et al., 2004; Haq et al., 2013).

A growing number of patients diagnosed with cancer prefer to participate in making decisions regarding their treatment and would rather know about different treatment options

(Tariman et al., 2014). One systematic review examining priorities of information needs of patients diagnosed with cancer found the top three informational needs are related to prognosis, diagnosis, and treatment options. The study also found that informational needs change over time. More informational support is needed to enable rural cancer patients to make informed decisions regarding their treatment after diagnosis, especially if there is a need to travel for treatment (Butow et al., 2012).

## **2.4 Social Domain**

The social domain relates to the patient's relationships with family and the community, and how these relationships may change with a cancer diagnosis (Fitch et al., 2009; Loughery and Woodgate, 2015). There are many benefits to individuals who live in rural areas. Rural residents can find a sense of belonging and comfort in living in rural areas. They often report feeling supported by the community and have close relationships with family, community members and religious institutions (Duggleby et al., 2011; Reid-Arndt & Cox, 2010). However, feelings of being a burden on family and friends, disruptions in family life, and feeling less connected with family and friends during long periods away are all common experiences of those living in rural areas with cancer (Butow et al., 2012; Loughery & Woodgate, 2015).

## **2.5 Practical Domain**

The practical domain addresses the assistance needed to complete tasks that would reduce demands on the individual diagnosed with cancer (Fitch et al., 2009; Loughery and Woodgate, 2015). Common practical challenges noted in the literature are travel, finances, accommodations in urban centers, work related challenges, and access to treatment close to home.

Cancer screening rates are lower in rural populations than urban resulting in later stages of some cancer diagnoses for rural women. Women living in rural areas, who are eligible to be

screened by mammography, are screened at lower rates and diagnosed at a later stage than their urban counterparts (Nguyen-Pham et al., 2014; Olson et al., 2012). This is due to lack of access to breast cancer screening services, less awareness of the importance of screening, and a delay in addressing symptoms due to other obligations (Depke et al., 2015; McConigley, et al., 2011; Nguyen-Pham et al., 2014). Cervical cancer screening rates are also lower in rural women (Decker et al., 2009). Logistical reasons, such as time, clinic hours and difficulty booking appointments, and social reasons, such as lack of social distance from care providers and little or no privacy or anonymity, are cited as reasons why participants did not receive adequate cervical cancer screening. However, in a recent Master of Public Health thesis, Rodriguez (2020) found that rurality was not a statistically significant factor in participation in cervical screening amongst women in rural Alberta. In one study, human papillomavirus self-collected testing was administered and was felt to address some of these barriers; however, the project did not address misinformation about cervical cancer or its treatments (Racey & Gesink, 2016).

Travelling for treatment can have an impact on treatment decisions. In three Canadian studies, breast cancer patients were noted to have lower rates of radiation therapy after surgery and mastectomy rates were found to be higher, possibly reflecting the difficulty in accessing radiation therapy that is typically required after breast conserving surgery (Forte, et al., 2014; Olson R., et al., 2012; Tyldesley & Mcgahan, 2010). In one qualitative study with women who had undergone either mastectomy or breast conserving surgery in Australia, those who had mastectomy saw travel as an extra burden, physically and emotionally, when they were not feeling well. They described the city as “lonely, isolating and daunting”, and said that travelling for radiotherapy would be an inconvenience (Ristevski et al., 2015, p. 293).

Travelling for treatment can cause emotional, financial, and work-related problems.

Travel often adds worry to an already burdensome diagnosis (Butow et al., 2012). Being away from home for extended periods of time for treatment is difficult for women in the rural context. The stress of running a home and parenting can be worse in rural women than their urban counterparts. Bad weather conditions, driving at night, and manoeuvring in an unknown city all added to the difficulties rural women faced when travelling for treatment (Gray et al., 2004).

The financial burden from a cancer diagnosis can be very distressing. This is highlighted in one Canadian study that examined the importance of out-of-pocket costs on cancer care decisions. The study found rural residents are twice as likely to report financial cost considerations in care decisions compared to urban residents. Rural residents in Canada are more likely to be seasonally or self-employed and therefore not as likely to be covered by group health plans, adding to the financial stress cancer patients are already facing (Matthews et al., 2009). In another Canadian study of breast cancer patients some of these same results were found. The women in these focus groups reported being upset about hidden costs, such as medications for side effects, as well as for accommodations and childcare while away. They also expressed the uniqueness of job situations in rural communities, which may include working part time jobs without benefits or job security or being self-employed. This left them with no options for taking time off for treatment or when sick (Gray et al., 2004).

Access to quality palliative care, that meets all of the domains from the supportive care framework, can also be difficult for those living in rural areas. According to Goodridge and Duggleby (2010), palliative care is not as accessible as it should be, even though there are proven benefits to palliative care programs. Barriers to palliative care include the lack of health care providers in rural areas, travel costs for patients to receive palliative care, predicting supplies and equipment needed by health care practitioners, and poor funding. In Saskatchewan, palliative

care and home care services were often found outside the community due to lack of accessibility and lack of continuity of care (Duggleby et al., 2010). Palliative radiotherapy, the treatment of symptoms by radiation therapy, has been shown to improve the quality of life of those dying from cancer but Lavergne et al. (2011) found that there is an inverse relationship between travel time and palliative radiotherapy in Nova Scotia, Canada. Travelling to receive quality palliative care is a reality for many Canadians. This requires a lot of preparation and extensive planning by both patients and their family care providers (Lockie et al., 2010; Pesut et al., 2010). Pesut et al. noted that “Participants described ways of making it work that included careful preparation for the trip, maximizing a routine, managing time and maintaining their significant relationships” (p. 191), when patients had to travel for palliative care. For caregivers, coping with travel was often difficult due to side effects experienced by sick family members, and the stress of travel often affected caregivers’ own health and wellbeing (Lockie et al., 2010).

## **2.6 Emotional and Psychological Domains**

The emotional and psychological domains address the need for comfort and reassurance and the need to cope with the situations related to a cancer diagnosis (Fitch et al., 2009; Loughery & Woodgate, 2015).

The psychological needs of those living with cancer vary with the type/stage of cancer diagnosed, the patient’s stage of life, and the geographical and environmental living circumstances of the patient. The supportive care needs of these individuals are also dependent on the patient’s point along the cancer continuum (Howell et al., 2012). Specialized psychosocial oncology support is important and necessary for cancer patients, but many health care providers in one Canadian study were not satisfied with the support offered to cancer patients in rural communities. Ninety five percent of the health care providers surveyed felt that access to

psychosocial care was important for oncology patients, but only 18% were satisfied with the psychosocial care their patients were receiving (Otfinowski, et al., 2003). General psychological care, such as therapists, psychologists, or counsellors, is uncommon in rural areas (Wilson et al., 2009)

Some challenges rural residents face, that urban residents, may not experience are embarrassment from lack of privacy from most people being acquaintances in a smaller community and only one place to access services, isolation while away from home, anxiety due to lack of services, and fear related to the uncertainty of travel and accommodations (Lougherty & Woodgate, 2015; Rogers-Clark, 2002). The lack of privacy, as well as lack of social distance from care providers, are reported as contributing to lower rates of cervical cancer screening in rural areas in Ontario (Racey & Gesink, 2016).

Stress, anxiety, and poor mental health were reflected in the international literature on rural cancer patients' psychosocial status. Rural residents with cancer in the United States report poorer mental health than their urban counterparts (Burris & Andrykowski, 2010). Anxiety around travelling for treatment and staying away from home, and feelings of isolation and distress from disruptions in family life can affect a rural cancer patient's quality of life (Butow et al., 2012; Lougherty & Woodgate, 2015; Wilkes et al., 2006). Accessing psychological supportive care, such as support groups or counselling services, which have been found to be beneficial, is often difficult. Many do not receive information on these groups or other options, such as video counselling (Fuchsia Howard et al., 2014; Stephen et al., 2013). The lack of mental health and psychological services in rural areas, paired with the mental health stigma noted by many rural residents, can result in services not being utilized (Reid-Arndt & Cox, 2010).

Disparities in mental health outcomes are apparent between rural cancer survivors and



their non-rural counterparts. Rural cancer survivors have been found to have more anxiety and depressive symptoms and greater distress than urban cancer survivors. Overall, rural residents with cancer have poorer mental health functioning (Burriss & Androwski, 2010). Fear of recurrence was common in cancer patients in follow up and survivorship. This fear was often complicated when living in a rural area due to lack of anonymity in small communities and the responses of community members to psychosocial concerns (Fuchsia et al., 2014).

Rural residence can have a positive impact on emotional well-being as well, particularly in the palliative setting. Those dying and their caregivers found it beneficial to stay in their community during palliative care and subsequent death. Being surrounded by family and friends in a familiar environment was found to be very important to these patients, as was feeling connected to the community and to rural healthcare providers (Duggleby et al., 2011; Wilson et al., 2009).

## **2.7 Spiritual Domain**

The spiritual domain addresses personal beliefs, finding purpose, and religious beliefs (Fitch et al., 2009; Loughery & Woodgate, 2015). Rural living in Canada can have positive effects on the spiritual well-being of individuals with cancer and their families. Feelings of being connected to the land, peaceful living, and balance are described as benefits by some living in rural areas (Rogers-Clark, 2002). Rural patients also describe feeling resilient and finding strength from being connected with their community. Overall, rural residents find value living in rural areas and find that it contributes to their overall well-being and spiritual wellness (Loughery & Woodgate 2015).

## **2.8 Summary**

The studies reviewed in this chapter provide valuable information about the supportive

care needs of those living in rural areas. By using Fitch's Supportive Care Framework for Cancer Care, themes among the literature were easily organized. Barriers to care and benefits of rural living were identified in the key domains of physical, informational, social, practical, psychological/ emotional, and spiritual.

In the physical domain, managing symptoms, specifically fatigue, was often difficult for oncology patients, especially if travel was required for treatment (Butow et al., 2012; Hall et al., 2013; Loughery & Woodgate, 2015). Rural people with cancer often have unmet informational needs, which is a problem because if the informational needs of individuals are met, their anxiety decreases. Several suggestions are given to reduce unmet informational needs, such as giving written information, giving information at the correct time, and giving information before the patient leaves home (Butow et al., 2012; Fletcher et al., 2017; Gray et al., 2004; Haq et al., 2013). Many benefits of rural living were discussed within the social domain. Rural residents feel they belong and are often part of close-knit groups of family and friends. However, when rural cancer patients must be away from home, they often feel lonely and less connected (Butow et al., 2012; Duggleby et al., 2011; Loughery & Woodgate, 2015; Reid-Arndt & Cox, 2010). Barriers to accessing care and having to travel for care made up the largest part of the discussion regarding practical care needs. Travelling for care, the burden of out-of-pocket costs, finding accommodations and balancing work, treatment and home life, and the lack of access to services close to home were discussed as unmet needs for rural oncology patients (Fitch et al., 2009; Loughery & Woodgate, 2015). In the emotional and psychological domain, one systematic review showed that rural oncology patients have poorer mental health functioning than urban cancer patients. It is often difficult to access oncology specific psychological support due to lack of services offered locally, combined with perceived lack of privacy (Burriss & Andrykowski,

2010; Butow et al., 2012; Fuchsia Howard et al., 2014). Rural residence can also help meet the emotional needs of those with cancer by facilitating feeling connected to friends, family, and the community (Duggleby et al., 2011; Wilson et al., 2009). Rural residents find benefit in living in rural areas and find that it contributes to their spiritual wellbeing (Loughery & Woodgate, 2015).

The literature review contributed to the researcher's current knowledge of rural cancer care. The studies demonstrate the need to address the barriers to good quality cancer care in rural areas. The many benefits of living in rural areas should not be discounted in meeting these needs. Suggestions from within this review have shown a need for rural specific policies and research to improve oncology care for rural patients.

## **CHAPTER THREE**

### **Method**

#### **3.1 Overview**

This study will use a qualitative inquiry approach. The naturalistic and constructivist nature of qualitative research aligns with gaining knowledge and a deeper understanding of the experiences of rural women with cancer (Thorne, Kirkham, & MacDonald-Emes, 1997). Using a qualitative approach allows the researcher to capture different dimensions of the experiences of those living in rural areas diagnosed with cancer and to place value on the individual experiencing the phenomena (Polit et al., 2012). Using the qualitative methodology of Interpretive Description (ID) allows a deeper understanding of the research question and of the met and unmet care needs of the women in the study.

This chapter covers the ID methods that were used for the study and discusses sampling, data collection, data analysis, and credibility. Situating self within the research role and the research setting will be discussed as well as confidentiality, storing and protecting data, and sorting and organizing data. The researcher will also explain the process of gaining ethical approval for the study.

#### **3.2 Interpretive Description**

The experiences of rural women navigating through a cancer diagnosis and treatment was examined using ID. Interpretive description is an alternate approach to other qualitative methods to better inform clinical and practical understanding of a phenomena (Thorne, 2016). It follows a constructivist and naturalistic orientation to subjective inquiry. The researcher attempts to make sense of the meanings participants have given to the experiences they have had and begins to construct an understanding of this data. Interpretive description assumes that realities are socially

constructed through the meanings of interactions with participants, the researcher, and the environment. Subjective and experiential knowledge is valued in ID (Thorne, 2016).

In ID, the researcher must acknowledge his or her place within the study. He or she must examine the practical or theoretical knowledge being brought to the study, as well as the personal relationship with the participant. The researcher acknowledges the influence both they and the participants have on the research process (Thorne et al., 1997; Thorne et al., 2004). Interpretive description acknowledges the shared and different realities of participants. The researcher seeks to understand shared experiences, while gaining knowledge from the individual variations in these experiences (Thorne, 2016).

The fundamental underpinnings of human experience and the production of knowledge outlined by Thorne (2016) was used to guide this study. They include: a) a setting that is both naturalistic and comfortable for participants and respects their ethical rights; b) valuing the subjective knowledge and experiences as a way of understanding clinical perceptions; c) understanding common experiences and expressions, as well as the wide variations often present; d) considering time and context within exploration of the experiences; e) recognizing that the social human experience is situated in its nature and cannot be separated; f) acknowledging that reality may be contradictory; and g) recognizing that the relationship between researcher and participants will influence interactions.

This ID is located within the existing knowledge of rural cancer care. The themes and patterns generated from this study will help to understand the challenges and potential direction of future clinical nursing practice in the rural oncology setting. According to Thorne (2016), “we seek patterns and themes within subjective human experience not so much as to grasp its essence as to understand what we are likely to encounter in future clinical practice and to have some meaningful sensitivity around it” (p. 79). New insights will potentially be generated as well, which will help to shape new inquiries about rural

health and cancer care in rural areas.

### ***3.2.1 Sampling***

Purposive sampling was used to recruit specific individuals, in this case women with cancer living in a rural area of Southern Saskatchewan, based on their experiences, aligning with the intent of ID to gain a rich understanding of their situations. Southern Saskatchewan is an extension of the vast grassland of the great plains. The economy of Southern Saskatchewan is made up of mostly agriculture and resource development (Saskatchewan Bureau of Statistics, 2021). To understand the experiences of rural women regarding their supportive care needs, purposive sampling was used, to ensure the participants experiences aligned with the objectives of the study and to produce findings that “have the potential of ringing true or seeming reasonable to your intended audience” (Thorne, 2016, p.91).

Only one participant was recruited using the recruitment poster (Appendix A, which were posted in the waiting room at the Allan Blair Cancer Centre and in all the patient rooms and the main area of the Cancer Patient Lodge. Snowball sampling, a form of purposive sampling, was therefore used after this participant contacted the researcher. This participant asked the researcher if she could post the recruitment poster on a social media group for those living in Saskatchewan with cancer. The remaining participants contacted the researcher after seeing this recruitment poster online. To be eligible to participate, participants had to be women diagnosed with cancer within the last five years, be over the age of 18, be able to speak and read in English, have the ability to provide informed consent, and be living in an area South of Davidson, Saskatchewan, outside the Regina commuting zone (>100 km), and in or outside of a town or village with a population less than 10,000 people. Participants who had been enrolled in a clinical research trial at the Allan Blair Cancer Centre (ABCC) were excluded from this study, as

the researcher was employed in this department at the time of recruitment.

Seven women agreed to participate in the study. With this sample size, a deeper understanding of the experiences of each participant was accomplished, while still finding shared realities between the participants' experiences. As Thorne (2016) states "if the background literature and disciplinary wisdom suggests that a certain phenomenon occurs commonly within clinical populations and what is needed is a more in-depth exploration of its underlying subjective experiential nature, then we can likely determine that engaging with a small number of individuals experientially familiar with it and willing to share that with us will produce something worth documenting" (p. 103). Time and resources required for a graduate research project were also considered when deciding on ending recruitment, as 2 months passed after the last participant contacted the researcher before ending recruitment.

### ***3.2.2 Dealing with data collection and data analysis***

While the researcher will address data collection and analysis separately, the researcher would like to note that data collection took place concurrently with data analysis. This iterative process is congruent with ID and other qualitative research methods. The researcher immersed herself in the data as soon as the first interview was completed and continually throughout the data collection process, which helped her explore knowledge from each interaction. Participants' interviews informed how concurrent interviews were collected. Specifically, the researcher asked the participants generally about their experience at the beginning of the interviews. This was done because the researcher found in the first interviews that participants felt they wanted to share their whole story in chronological order, and then come back to answering the interview questions. The interviewer reflected on her own interview skills and adjusted to listen to participants more throughout the interview and ask participants to expand on some topics

throughout the interviews.

### **3.3 Situating Self in the Research Role**

The researcher's background as an oncology nurse, combined with first-hand experiences of a close family member receiving cancer care while living in a rural area, formed the basis of the idea for this study. Thorne (2016) states "In most instances, people (study participants) will be the primary source of data, and a fascination for people within the clinical context is most likely what inspired the study in the first place" (p118). However, as Thorne warns, for the study to be credible and meaningful, the researcher must abandon this background. Some of the issues that may present themselves when using ID, including: a) tracking reflections b) learning not to lead c) disclosing the discipline d) revealing and concealing e) negotiating informed consent f) finding your tongue and g) constraining your influence, are discussed below (Thorne, 2016).

#### ***3.3.1 Tracking reflections***

The process of documenting the "nature and substance of the ideas" the researcher holds about what is being studied was done by keeping a reflective research journal, also referred to as field notes at times. The researcher documented in this journal before the interviews began, during data collection, and throughout data analysis. This assisted the researcher in the inductive research process (Thorne, 2016, p. 119). The reflective journal kept by the researcher was a way to reflect on the potential biases the researcher may have had, specifically from working as an oncology nurse and from personal experiences.

#### ***3.3.2 Learning not to lead***

As an experienced nurse working in oncology, the researcher was taking the lead on conversations about cancer care and treatment with patients. Thorne describes the difficult process of "undoing" the role of expert clinician and instead taking on the new role, where the



participants are the experts (2016, p. 119). Not leading the participants in the interviews and not bringing expertise as an oncology nurse took practice, coaching, and guidance from the researcher's thesis supervisor.

### ***3.3.3 Disclosing the discipline***

The researcher carefully considered the potential risks that would be brought to the research study, particularly the need to disassociate from the role of oncology nurse. It was important for the researcher to be honest with participants about the reasons the researcher is interested in studying the phenomena, but also to avoid "inappropriate expectations", which in this situation would most likely involve the participants using the time with the researcher to discuss or share ideas that would not contribute to the purpose of the study. The researcher did share with the participants that she was a nurse who had experience in oncology, but by "setting and maintaining appropriate boundaries" with the research participants, the researcher did not encounter the above issue (Thorne, 2016, p. 111).

### ***3.3.4 Stepping out of the role***

Using the reflective research journal, the researcher was able to critically examine if there were any interactions she had with the participants that may have crossed from "learner side" to "clinician side" (Thorne, 2016, p. 112). The researcher planned to delay any informational responses that she would know only from being an oncology nurse until the end of the interview. Neither of these situations was encountered.

### ***3.3.5 Revealing and Concealing***

The researcher shared with the participants that she was a nurse who had worked in oncology, as all of the participants asked. Before beginning the interview, the researcher explicitly explained again that the purpose of the study was to understand the women's own

experiences. On one occasion, one of the participants stated, “I guess you may know that because of your work” (*Participant 6*). The researcher asked the participant to explain more, and reiterated that it was her experience the researcher was interested in. The participant then divulged more information about the topic of discussion.

### ***3.3.6 Negotiating informed consent***

Thorne (2016) discusses suggestions to address informed consent, and how to negotiate it throughout the data collection process. Thorne states the researcher has an “ongoing moral obligation, enacted in verbal as well as non-verbal behavior, with the goal of creating optimal conditions to ensure that the people we study reveal what they are comfortable with and no more” (p. 114). The researcher reviewed the consent form with participants before the first and second interviews. The researcher also reminded participants they could pause the recording at any time, decline to answer any questions, withdraw if they no longer felt comfortable being part of the study, and decline to participate in the second interview. Three of the research participants declined to participate in the second interview when the researcher called to schedule it; all stated they did not feel that they had more to contribute.

### ***3.3.7 Finding your tongue***

Thorne (2016) encourages qualitative researchers “to prompt for further clarification or elaboration rather than to signal that you understand completely” (p 115). To address this, the researcher developed “good questions” as suggested by Thorne, to encourage reflection and deeper communication and to show the researcher is interested in the study participants’ thoughts. The researcher also used Thorne’s suggestion to make connections between interviews, by introducing anonymous concepts from previous interviews and asking participants thoughts on this. This was particularly applied in regard to travel, as this was a common theme brought

up by all participants (Thorne, 2016).

### ***3.3.8 Constraining your influence***

Before commencing this study, the researcher carefully acknowledged and examined the ideas she had about rural oncology care. This reflection continued throughout the research process. The researcher comes to this study as a female nurse who has lived in rural Saskatchewan. She has had experiences with family members undergoing cancer treatment while living in rural areas. By reflecting upon the experiences the researcher personally had in rural health care, both as a nurse and as a family member, she realized the potential influences on interactions with the study participants. Personal experiences and disparities witnessed in rural health are what makes the researcher passionate about this research. However, the researcher needed to ensure she was not looking to validate and compare experiences with the participants. Continually self-reflecting throughout all areas of this research process helped to ensure this.

### **3.4 Situating self in the setting**

The setting for this study was the ABCC and the Cancer Patient Lodge, both located in Regina, Saskatchewan. Initial appointments for most patients diagnosed with cancer in Southern Saskatchewan take place at the ABCC so rural patients would have access to the recruitment posters at these appointments. The Cancer Patient Lodge provides accommodation for those living outside the city. As per Thorne (2016) “clinical researchers often have a misguided optimism about ease of entry and access” to the research field (p. 116). The researcher felt, before recruitment started, that she would achieve recruitment quickly, based on her “insider” experiences in the clinical trials department at the cancer clinic and other nursing roles within the ABCC. As discussed earlier, this was not the case. The researcher spoke with the manager of support services, who manages volunteer services at the ABCC, and the manager of the Cancer

Patient Lodge. Although Thorne warns that the researcher may be viewed as a nuisance when “navigating access” to the research site, the researcher did not encounter this. Both contacts the researcher spoke with were glad to assist in distributing recruitment posters and were interested to hear about the study.

Data collection was conducted in the participants’ homes. A space was offered at the University of Saskatchewan School of Nursing campus in Regina, but most participants were no longer travelling for treatment, so would have had to make the trip for only the interview, and those that were travelling felt they would be too fatigued to do the interview during their trips for treatment. In the research proposal, it was stated the interviews would take place at a location that was mutually comfortable for the researcher and participant. Although this addressed the issues that may arise with observing participants in the clinical setting, it did bring forward some of the concerns Thorne discusses around “Staying Safe”. The researcher had a safety plan in place which included family members knowing where she was and when she was expected to be home, access to a cell phone at all times for emergencies, and an escape plan if things were not going as planned and the researcher felt unsafe.

When addressing “Honoring Confidentiality”, Thorne speaks of the “gray zone”, outside of the explicit requirements of confidentiality within the health care system and the ethics of the study. Examples of this include perceptions of clinicians, of other patients, or about the setting that treatment took place in. Thorne addresses the complicated nature of institutional confidentiality and discusses the value of using multiple sites or not using the specific name of the facility. Due to the nature of cancer care in Saskatchewan, and that the study specifically states women from Southern Saskatchewan will be interviewed, it was not possible to de-identify the facility where many of the women received treatment. However, no names of individual

clinicians, or of the facilities that were accessed in local rural areas, were identified in the study (Thorne, 2016).

### **3.5 Data Collection**

#### ***3.5.1 Access and confidentiality***

The researcher provided the manager of support services and the manager of the Cancer Patient Lodge with the recruitment posters (Appendix C) and a short explanation of the study with instructions to direct any inquiries to the researcher, whose contact information was on the recruitment poster. As described above, one participant contacted the researcher from the recruitment posters posted, and the remaining participants contacted the researcher after seeing the recruitment poster on social media which was posted by ‘participant zero’. Potential participants were then provided with the consent form, which included potential risks and benefits of participation, length of study, data collection procedure, and time commitment. The researcher also discussed research goals and purpose, data analysis, and how the data would be used with potential participants before they agreed to participate in the study.

It was clear in the consent form given to participants that confidentiality would be maintained throughout the entire research process. Participants were also reminded at the time of signing the consent as well as prior to the first interview that they would withdraw at any time.

#### ***3.5.2 Interviewing***

To answer the research question of this study, the researcher felt that one on one, semi structured interviews, with a follow up interview, would be the best data collection method. This would ensure the researcher would gain in depth understanding of the experiences of rural women that had cancer. The one to one interview provided a safe place to explore feelings related to the care they had received.

As the researcher is new to research, the wide breadth of data available on conducting quality interviews for qualitative research was a consideration in the decision to use interviews. It was also noted that both differences in experiences and similarities could be explored using this method.

Participation in the study involved one in person in-depth, semi structured interview, using open ended questions. A total of eleven open-ended, semi-structured interviews were conducted with seven participants. A guide with open-ended questions was used to assist in exploring the topic with participants, but unplanned questions and prompts were used when appropriate (Appendix C). All seven participants took part in in-person interviews which were digitally recorded and lasted between 45 and 60 minutes. Four of the participants participated in a follow-up phone call interview approximately two weeks after the first interview, which allowed the researcher to clarify aspects of the first interview and explore the participants' perceptions in greater depth. The remaining three participants declined the second interview, stating they did not feel they had anything more to talk about. The follow-up phone call interviews were unstructured, and questions were based on the answers to the individual woman's first interview. All recordings were transcribed verbatim for analysis. The participants were given the opportunity to review their transcripts, but none choose to.

The researcher was careful to examine the prompts she used, as well as other conditions that may have affected what the participants shared in the interview. This included using the reflective journal before and after interviewing the participants, being aware-of initial interpretations and correcting them, while remaining neutral in the interactions with participants to be sure that researcher did not "steer the interactions in predictable directions" (Thorne, 2016, p. 129). The researcher was also careful to focus on the participants allowing them to share their

stories in the order and manner of their choosing, not always specific to the order of the semi structured questions. For many of the women, it was important to them to tell the researcher their story of diagnosis and the beginning of their treatment journey. Thorne (2016) speaks to this and warns to not become impatient as this context can provide a deeper understanding for the researcher. Interpretive description requires ongoing reflexivity, and the researcher's reflection in the journal after each interview was one way the researcher met these criteria (Thorne, 2016).

### ***3.5.3 Managing and protecting data***

Written data obtained from this study was kept in a secure locked cabinet. The documents will be kept for a period of five years, and then will be destroyed. The audio taped interviews, which were in digital format, and the reflective journaling and field notes of the researcher were stored digitally and password protected. The researcher will not share any personal information obtained in the research process with anyone outside of the researcher's thesis committee. All identifying characteristics, such as consent forms, were separated from the data when it was transcribed to ensure anonymity of participants.

### ***3.5.4 Sorting and organization***

The researcher used a basic word processing software and highlighting techniques within it to sort and organize the data. The data was dealt with immediately after each interview to be sure the researcher did not become overwhelmed. This included transcribing the interviews as soon as possible after completing them.

## **3.6 Data Analysis**

According to Thorne et al., (2004), the main tasks of data analysis in an ID study are to understand the data, synthesize the data, theorize about relationships between the data and meanings of the data, and then contextualize these theories into findings. Analysis of the data

occurred concurrently while conducting interviews with the participants and was continually analyzed throughout the whole data collection and after. The knowledge and ideas the researcher had, both from working in oncology care and from working and living in a rural area, were noted and carefully examined to be sure they did not affect what was heard from participants. This iterative approach was continuous through the whole research process.

Commonalities and patterns were uncovered, and the researcher used highlighting as well as reflection in the research journal to work and rework these into themes. Themes were inductively derived from analysis of the interviews. Coding was not used as it was thought by the researcher that the voices of the participants may be lost. Potential data elements were flagged throughout data collection as potentially meaningful using the researchers field notes. Using cut and paste on a basic word processor, elements of the interview were pasted into different folders titled with the theme or subtheme. These themes were reworked several times. Repeated immersion in the data occurred to avoid superficial analysis. The researcher's attention alternated between the individual cases and data as a whole to avoid making links too soon or that were too superficial. This approach encouraged broader based themes and greater reflection (Thorne, 2016).

### **3.7 Enhancing Credibility**

Thorne (2016) turns to epistemological integrity, representative credibility, analytic logic, and interpretive authority as general guiding principles to evaluate a study for credibility. This study follows a logical research process to answer the research question "What are the perceptions of women living with a cancer diagnosis in rural Southern Saskatchewan regarding their met and unmet care needs?" The semi structured interview questions address the domains in The Supportive Care Framework. The researcher critically reflected on how her work as a nurse



and experiences in oncology nursing may affect the data collection and interpretation. She provided reasoning, through the reflective journal, of what knowledge was from this and what knowledge was from the literature review and was careful to not let this affect the inductive research process.

Representative credibility should be shown in that the conclusions from the research are consistent with the how the study was sampled. As this is a master's level study and there were time constraints, this was achieved through the follow up phone call interview, which challenged the researcher's initial conceptualizations from the first interview by allowing the researcher to ask any further questions in regards to the content of the first interview. Triangulation of the findings with the current literature assisted in strengthening the credibility of this study. The reflective research journal kept by the researcher from data collection through to data analysis explained the reasoning for the interpretations in this research study and that an inductive process was followed. The journal provides transparency and justifies the steps and decisions through the research process. The verbatim transcription records were also retained to answer to analytic logic. Southern Saskatchewan is similar to other parts of rural Saskatchewan in regard to demographics, which enhances the transferability of the results of this study.

To address interpretive authority, the researcher immersed herself in the data, by reading and re-reading the transcripts continually throughout data collection and analysis. The researcher carefully examined her biases and reflected on her personal and professional experience. The researcher grew up in a rural community in Saskatchewan and was a caregiver for a close family member with cancer. The researcher is also an oncology nurse and has cared for both rural and urban patients with cancer in this context. It was important to ensure that these experiences did not affect the research outcome. Careful reflection using the research journal ensured the

researcher was aware of preconceived bias and feelings. These preconceptions included the assumption that travel was a burden for all participants, that the lack of access to services rurally would be frustrating and cause distress, and that participants may feel helpless living in a rural area with cancer. Using this reflection, the researcher sought to suspend these biases and feelings to ensure she was hearing what the women were actually saying. The researcher was also in close contact with her thesis supervisor to assist in analytic thinking throughout the research process. Throughout data analysis and after, the researcher asked herself general questions, such as “What is being seen?” and “Why its being seen?” to ensure inductive reasoning was followed.

This study reveals an interpretive authority by thoroughly studying the literature review to situate the knowledge gained within it. The researcher also acknowledges where she places herself within the research, and by continually evaluating this will “account for the reactivity that will occur within the research processes” (Thorne, 2016, p.225). The researcher also sought advice and input from the supervisory team throughout the entire research process.

### **3.8 Ethical Approval**

This study was submitted to and approved by the University of Saskatchewan Behavioural Research Ethics Board, which is harmonized with the Saskatchewan Cancer Agency Ethics Committee. The researcher submitted the consent form, informational posters, and sample interview questions to the Ethic Board.

The consent form followed the guidelines provided by the University of Saskatchewan Behavioural Research Ethics Board. It highlighted the potential benefits and risks of participation, confidentiality, storage of data, and that participants have the right to withdraw at any time until data analysis has begun. The consent form was discussed in depth with each participant, and participants were given opportunity to ask questions and discuss the proposed

study before signing the consent form. A copy of the consent form including contact information was given to the participant so they could contact the principal investigator or ethics office at any time. As previously stated, the researcher is employed at the Saskatchewan Cancer Agency in the clinical research department. Potential participants who were enrolled in or have ever been enrolled in a clinical trial at the ABCC were not eligible to participate in this study to ensure no patients that the researcher had contact with at her place of employment will overlap with this study.

Reassurance was given before signing the consent and throughout the research process that participation was completely voluntary and they could withdraw at any time without negative consequences. It was shared with participants that they may not directly benefit from participating in this research study. There was a risk that participants may feel uncomfortable reflecting on their experiences. The researcher discussed this with participants at the beginning of each interview, and informed participants that a social worker at the ABCC could be contacted for support. None of the participants appeared to be uncomfortable or emotional during the interviews, and all denied wanting support after the interview.

### **3.9 Chapter Summary**

This chapter discussed the research methodology of ID as it was applied to this research. The strengths and weaknesses of the data collection method chosen, and the process of interviewing, were discussed. The researcher highlighted the importance of the reflective research journal and how it was used throughout the entire research process. Thorne's concept of "situating myself in the research" assisted the researcher in addressing challenges throughout the research process. The process of ethical approval for this study was discussed as well.

## CHAPTER FOUR

### The Results

#### 4.1 Overview

The following chapter will discuss the findings from this study. Eleven interviews were conducted with seven women who lived in rural areas of Southern Saskatchewan and had been diagnosed with cancer within the past 5 years. The interviews were conducted between July 16, 2019 and November 18, 2019. Two of the women had palliative diagnoses and five of the women had curable diagnoses. These five women were all done treatment at the time of the interview.

The data collected from the interviews and follow up phone calls was analyzed. Four themes were identified from the data: Feelings – ‘From normal life to chaos’; Self-efficacy and Resiliency – ‘Get up and get going ‘cause there’s things to do’; Timing – ‘And then the whole month was just waiting’; and Access – ‘For the most part, you just drive’. The themes and their associated sub-themes will be discussed in the following sections.

#### 4.2 Feelings: “From normal life to chaos”

The women spoke of the emotions they had from diagnosis until present time during the interview. There was a wide range of feelings for all participants. Subthemes of feelings included anxiety and worry; loneliness; humour; and gratitude and hope.

##### *4.2.1 Anxiety and worry*

Within the sub-theme of ‘anxiety and worry’, all of the women expressed feeling worried or having feelings of anxiety at some point in their cancer journey. A common circumstance leading to feelings of worry or anxiety was immediately after the initial testing while waiting for results. One participant (Participant 1) said “*I didn’t really think I worried that much but I did. It*

*turned from normal life to chaos overnight. And scary, scary chaos*". Another participant stated, *"I had to wait to find out, whether it was cancer, which I'm sure you're being told from everyone you've spoken to, that is one of the toughest times"* (Participant 7).

The participants that had a curative diagnosis spoke of the worry of recurrence. One participant said, *"Every time a bone hurts, I go, I wonder what that is, you know, because from what I've gathered if it does recur it will be bone, liver or lung mostly"* (Participant 4). Another participant said, *"There's a lingering feeling that you've had cancer, it will probably never completely leave"* (Participant 7). The participants with a palliative diagnosis spoke of worry of progression *"It's always in the back of your mind, how much time do I have? Where's it going now? That hurts, what is it?"* (Participant 5).

Two of the women told of medical mistakes that caused anxiety and stress. Some of the women spoke of the effects that staff had on the participant's stress level. For example, one participant spoke of the front desk staff at one clinic not being friendly and how this was a hard start to an appointment. Another participant spoke of feeling that health care providers seemed too busy in the urban inpatient centre and that they could not ask questions.

One of the participants spoke of a lack of support from both their employer and their spouse's employer. She said this was very stressful for them both.

#### ***4.2.2 Loneliness***

The participants spoke of the loneliness they had experienced after diagnosis and throughout treatment. One participant described right after diagnosis as *"a long time, scary time, and feeling all alone and out there just waiting"* (Participant 1). One of the participants who had a palliative diagnosis spoke of the loneliness of being diagnosed with stage four cancer. She spoke of being uncomfortable speaking to her family about her palliative diagnosis and that a lot

of the supports were for those with early stage. *“I always feel like the rain cloud in the room”* (Participant 5).

One participant spoke of the impact health care professionals had on her emotional state. *“You just want to be loved. Those girls should be acting like it’s a good day and they weren’t”* (Participant 1).

#### ***4.2.3 Humour***

All of the women used humour throughout the interviews. Some of this humour was around living in a rural area. One participant joked about the drive, *“Well it’s probably closer to three hours but when [husband] drives it’s about two and a half”* (Participant 1). One participant joked about having early appointments, *“Now I’ll be able to find a better parking, that was the only good thing”* (Participant 2). One of the women spoke of sending her husband home from the city back to the farm during seeding season, *“Here I am sitting in the city waiting to get trained to put this IV in, etc., and he had someone drive him home”* (Participant 3). The mobile mammogram bus was referred to as the *“boob mobile”* by two participants (Participants 1 & 4). Another discussed becoming involved *“Cause I needed something else to do”* (Participant 6), referring to organizing some community events. One participant found it humorous that the staff at the ABCC told her to go to her local hospital half an hour early to get through admitting, which was not necessary in her small hospital.

#### ***4.2.4 Gratitude and hope***

All women interviewed expressed gratitude for the various health care providers they had encountered. One participant spoke of the gratitude she felt towards her oncologist at the first appointment *“I’m sure it was two hours he spent with us that afternoon, all three of those healthcare professionals and I’m sure people waited that day but I needed that”* (Participant 6).

One woman spoke of having a different outlook after her cancer treatment. *“When I got better and I could enjoy everything. I felt kind of high on life. Does that have anything to do with cancer, probably, because I have a different outlook on life”* (Participant 1).

Another participant spoke of how grateful she was to the radiation therapy staff. She spoke of having to be away from home for her treatments and how supported she felt by the radiation therapists.

### **4.3 Self-Efficacy and Resiliency: “Get up and get going 'cause there’s things to do”**

When the women in this study were describing their experiences, the researcher sensed the “toughness” of all women. Although the participants expressed frustration with many parts of their cancer journey so far, they did not complain. Most of the women spoke of being very involved in their own care. The subthemes within this theme are advocating for better care; “doing what has to be done”, and concern for others.

#### ***4.3.1 Advocating for better care***

The participants spoke of advocating for better care for themselves in different ways. Many of the participants spoke of advocating for themselves to avoid travelling unnecessarily. One of the women said, *“I said can you just phone me with the results, which is what he finally did”* (Participant 2). Another participant told of requesting her treatment to be back in her local community after her chemotherapy had been changed.

Some of the women spoke of questioning their treatment plan. One woman questioned why the surgeon decided to perform the surgery she did. *“I think back and think hmm given my circumstances, when I finally realized them, did they have the wrong file. Because I should have never been a lumpectomy candidate but that’s what they recommended”* (Participant 1). Another participant spoke of having an MRI scheduled very close to her surgery date, which was

concerning as the specialist would not have the results before her surgery. One participant received a second opinion with Best Doctors through her insurance. She used this advice to advocate for her treatment.

Many of the participants spoke of questioning whether their family physician was up to date on cancer care. However, the women that spoke of this were forgiving of it and understanding.

Some of the women spoke of how they had asked for things for themselves throughout the process. For example, one woman said, *“I had my GP refer me to the occupational therapist because, you know, because I didn’t get a lot of exercises”* (Participant 3). Another participant spoke with the manager of chemotherapy to have the location of her chemotherapy changed to Regina from her rural location. Because her oncologist did not do appointments by telehealth, she was going to have travel to Regina for her oncologist appointment, go home, and then travel for her treatment for approximately an hour the following day. The patient took it upon herself to speak with the manager of the chemotherapy department to request to have her treatments in Regina, as she was going to have to travel to Regina for her oncologist appointment, go home, then travel the next day for approximately an hour for treatment.

One of the participants with metastatic disease made lifestyle changes. She said that she had to research this approach for herself and did not receive help from the formal health care system team. When speaking about the changes she made, it was clear to the researcher that it would have been a huge amount of time and energy to find all the information she had, but she simply stated, *“I just worked at it, it’s not an impossible thing to do”* (Participant 5).

#### ***4.3.2 “Doing what has to be done”***

Many of the participants spoke of “powering through” or “doing what had to be done”.



One woman spoke of driving herself to appointments because her husband and children were working, and she felt she had no other choice. Another spoke of recovering from surgery during harvest. *“It’s a busy time of year, you’re making meals and everybody’s coming and going and so that was not easy”* (Participant 3) and then she added *“But like everything else, you live through it.”*

One participant spoke of resuming community activities before she was ready as there was a small number of volunteers in her rural community to keep these activities running. The same participant spoke of returning to work before she was ready due to being out of sick time. She stated that financially, she had to return to work. Another participant spoke of returning to work because she knew her co workers were working short staffed as her employer could not find anyone to cover her while she was off.

#### ***4.3.3 Concern for others***

All of the participants spoke of being concerned for others in the same or worse situations. *“I think you have to be your own advocate but I think there’s probably lots that aren’t”* (Participant 1). One of the participants stated, *“I was pretty fortunate, other people are going through so much more”* (Participant 7). Two of the participants who were retired spoke of being concerned for younger women diagnosed with cancer who would have to juggle young kids, work and cancer treatment. *“Like, they’re going through way more than I did and trying to deal with kids, my God”* (Participant 7).

Many of the women in the study spoke of giving back to others. *“My belief is that you have to pay back. Because people were so good to me when I went after my diagnosis and treatment, I make a point of helping people when they’re newly diagnosed”* (Participant 4). Another participant spoke of giving back through fundraising and the Run for the Cure. *“I was*

*like, having gone through what I went through, I'm going to give back. Like I did this, I survived it, so I'm going to help people that need it" (Participant 6).* One of the women spoke of the tightknit rural community she lived in and that they provided support to each other, especially survivors that had *"already been through it" (Participant 1).*

One of the participants spoke of the long wait to see her oncologist on the day of her appointments, but that she was very forgiving of this wait. *"Like, I would never complain. Somebody is in there getting their bad news and needs the support and I'm so grateful that they give that much support because not all doctors do."* (Participant 6)

#### **4.4 Timing: "And then the whole month was just waiting"**

Within the theme of timing, participants spoke of the timing of receiving information, which included too much information at one time, not receiving information early enough or when needed, and waiting for services.

##### ***4.4.1 Timing of information***

Most of the participants spoke of being overwhelmed with too much information at once. *"They hand you a paper on all the thousands of side effects of this particular drug and if it (the side effect) isn't on there I'm just going to assume its something else."* (Participant 1)

Some of the participants spoke of needing information earlier than it was received. *"I remember thinking they needed to have a liaison or a social worker in place for you or someone there for you from the day you got that information from your family doctor, that you had cancer, because there's some dark days from there until you finally get to Regina to find out more" (Participant 1).* Another participant said *"I don't know how it could be improved, but it seems there should be some way of putting all that information together. How do you do that when you don't even know what information you need? You, the patient would have to sift*

*through it I guess” (Participant 3).*

One participant spoke of the anxiety she felt when she was called with her surgery instructions. She stated *“all the instructions were rushed, so they said, Oh, just call them never back if you have any questions later. But when I tried that, I kept getting a message that the number was out of service (Participant 7).* The participant said, because of this, she did not feel prepared for her surgery and did not understand exactly what was involved.

Two of the participants spoke of the lack of coordination of information between all the health care services they were accessing and that they thought there should be a system for giving information at the correct times between their family physician, surgeon, and oncologist. Two of the participants expressed frustration that the bloodwork being done for chemotherapy was not available to be viewed by the family physician. One participant said *“I’ve just given up on trying to get them (tumour markers) because they don’t include my family doctor in this blood work. So I can’t just go here and get it and to get it to get from Allan Blair is always such a process” (Participant 5).* One of the participants said she now uses the new system by e-health to check her own bloodwork. The other participant added her family physician to the bloodwork requisitions herself. One of the women spoke of receiving a call for an appointment with the ABCC before she had even received her pathology results.

#### ***4.4.2 Waiting for services***

Three of the participants spoke of waiting a very long time for their pathology results. One participant spoke of waiting after her abnormal mammogram for a biopsy in Regina and then waiting again for the biopsy results. She said *“I remember my doctor telling me when he called me back from the screening mobile saying ‘Oh no, they’ll call ya in quickly’ and it wasn’t quick (Participant 1).*

Another spoke about the wait for her pathology results, saying *“I would have really hoped they would have made that a little quicker”* (Participant 7).

Participants spoke of waiting at different times during their diagnosis and treatment. *“And then the whole month was just appointments and waiting”* (Participant 1). One participant told of waiting to get a port-a-cath, which is a device implanted to receive chemotherapy, put in, and having a peripherally inserted central catheter (PICC) put in instead as she was told it was quicker. One of the participants spoke of wanting a second opinion but feeling that she had already waited too long to see her first surgeon did not feel she had more time to wait to see another. Another spoke of questioning the decision her surgeon had made regarding a mastectomy but proceeded as she was not willing to wait for a double mastectomy. One participant spoke of waiting to have further testing until she had an oncologist appointment.

#### **4.5 Access: “For the most part, you just drive”**

The participants spoke of the difficulty in accessing different supports and services throughout their diagnosis, treatment, and follow up. All of the participants spoke of having to travel and the considerations related to this. The participants spoke of the difficulty they had accessing information regarding their cancer and treatment. They also spoke of utilizing different supports and services and how, at times, these were difficult to access due to many reasons, but that health care providers made some supports and services easier to access,

##### ***4.5.1 Travel***

As aptly stated by Participant 5, *“For the most part, you just drive”*, which seemed to overarch the sub-theme of travel as it impacts on access. All of the women interviewed had to travel at some point for diagnosis and/or treatment. Most had to travel for a biopsy to confirm malignancy after the initial scans. The most frequent place to travel to was Regina for treatment;

however, some reported having to travel to access their family physicians and some had to travel to Saskatoon for tests or procedures.

Some of the participants spoke of having health care providers that were accommodating for travel. For example, Participant 1 stated *“I did feel that he (surgeon) was mindful of the fact that I lived far way and they would try their hardest to make sure I could get tests and have things done on the same day.”*

The women in the study questioned the need for travel at times. *“I had to go back several times to see the surgeon and every time he just removed a couple of staples”* (Participant 2). Some of the participants spoke of having to leave for appointments before the office or clinic was open, and finding out, after they had left, that the appointment was not necessary or that their treatment had changed. *“There’s nobody there when you need to leave in the morning, so they called me when I was half an hour away saying they don’t have the pathology”* (Participant 7). Another participant stated, *“We got as far as [Town] when they called to say that my blood was no good and I could not have treatment”* (Participant 2). The same participant spoke of having a treatment change that she was not aware of, which could have been administered in her local hospital and may have averted the need to travel to Regina.

The participants spoke of the burden of long trips during treatment. One participant had to travel to Saskatoon for testing and referred to it as *“a two day affair”* (Participant 2). Another participant spoke of feeling she recovered more quickly after treatment when she received treatment in her local community, rather than having to travel.

The participants also spoke of a lack of understanding of the burden of travel by healthcare professionals. *“I did have one treatment in Regina at 9 AM. I told them I had a two-and-a-half-hour drive”* (Participant 2). The participant did say that after asking for appointment

changes, the staff were accommodating. Others reflected on how the healthcare team seemed to not fully comprehend the implications of their before and after drives. For example, one participant had complications after surgery so had to travel to Regina to see the surgeon, explaining her discomfort further complicated by the burden this trip placed on family, as it was in the middle of harvest. The participants spoke of the stress of having to travel last minute for care. *“Every time I’ve had a PET scan they’ve called me the day before and said, ‘can you be here for tomorrow?’. So it’s basically drop what you’re doing, pack up and go” (Participant 2).* Two of the participants spoke of worrying about driving in the winter, while another spoke of her experiences travelling home from treatment with nausea and fatigue. She summarized this as *“The drive home was brutal” (Participant 6).*

A number of access and non-direct care issues were also highlighted within this sub-theme. One participant spoke of the disappointment she had that the STC bus service was no longer available. She said *“The treatments weren’t all that severe so I easily could have taken the bus that we used to have here in town. I thought that would have stressed me much less than asking people to drive me” (Participant 7).* Some of the participants spoke of having to travel for supportive care or for treatment for symptoms. *“I’m having huge dental issues because of the bisphosphonate and the dentist here won’t touch me. He won’t even discuss it, just sends me straight to the oral surgeon in Regina. It’s like everybody that deals with the side effects is in the cities” (Participant 5).*

The cost of travelling for treatment was discussed in most of the interviews. Gas, parking fees, and meals were all mentioned as furthering the burden when travel was required. One of the participants spoke of having to travel for cancer fundraising, specifically Run for the Cure.

Women felt their access through travel was intimately aligned with the support of others.

One participant spoke of being too tired after scans to drive herself home so always had to have a family member drive her. One of the participants spoke of relying on family and friends to drive her to the city for appointments due to her not being comfortable driving in the city. This same participant stayed with friends in the city during her radiation treatments and spoke of feeling like a burden on these friends. Some of the participants were part of farming families. They spoke of the stress of having to travel for appointments during seeding or harvest. One participant, who had to travel to see her family physician, said *“Well we weren’t going to stop harvest to drive up for a five-minute appointment that you’re not really going to tell me anything” (Participant 7).*

There was a general theme between all of the participants that, although travel was at times a burden, it was necessary. Some of the participants also spoke of being grateful to the time spent alone with family or friends during their time travelling.

#### ***4.5.2 Travel alternatives***

Several of the women were diagnosed using the mobile mammogram screening service. All of the participants who used this service were satisfied with the care they received.

Examples of travel alternatives shared by the participants included the mobile mammogram service and having treatment provided locally. Also, one of the participants spoke of being admitted after having an abnormal test, and that she felt this was decision was made because she was from a rural area. One of the participants found that the Community Oncology Program of Saskatchewan was not beneficial, as her oncologist would not conduct reviews by telehealth. Therefore, she would travel to Regina to see her oncologist, and then again the following day travel approximately one hour to receive her treatment through the community-based program. The participant expressed her frustration with this *“I thought it was totally*

*bizarre and ridiculous, why were they putting all these extra miles on me. Particularly since I couldn't see my oncologist through telehealth*" (Participant 1). However, another participant felt that having treatment closer to home was beneficial as *"The difference between having my treatment in [rural area] is I can drive myself, in Regina I can't especially well, just being very, very tired"* (Participant 2). Most of the participants spoke of the benefits of telehealth. *"It's way better than having to drive in for, you know, a 15-minute appointment"* (Participant 5). Another participant stated, *"It was really nice that they were so good at telehealth because it saved us a lot of travel"* (Participant 6). However, there were some negative aspects of telehealth.

Participants spoke of seeing a different oncologist every telehealth appointment, having to travel even for telehealth, and a lack of information and communication regarding telehealth appointments. An example related to one participant did not know she was to see her family physician for a physical assessment before her telehealth appointment with her oncologist.

Some of the participants spoke of calling the cancer clinic for various reasons and being very satisfied with how quickly staff at the cancer clinic got back to them. One participant, who was on an oral form of chemotherapy, relayed her experience of speaking to the pharmacists at the cancer center by phone, which was beneficial both in terms of receiving the information in a timely manner and averting the need to travel to see the pharmacist. Another participant spoke of a similar experience, but with respect to medications to treat her side effects. She said, *"I called and talked to someone and then the on-call oncologist sent a prescription for ondansetron to my pharmacy here"* (Participant 6). One participant spoke of using the on-call service at the Cancer Clinic as being very beneficial.

Some participants spoke of the convenience in staying at the cancer patient lodge during their treatments. All of the participants spoke of being very satisfied with these accommodations.



One participant said *“I cannot say enough good things about the lodge and to me it was a vacation, radiation vacation we called it, probably the best time I had in my whole year of, shall I say, hell (Participant 1).* The benefits the participants spoke of included a reduction in travel and sharing experiences with others in the same situation, as well as significant cost savings.

#### ***4.5.3 Access to information***

Many of the participants spoke of the difficulty of accessing information related to their diagnosis and treatment. One participant stated *“I can’t say that I had trouble getting the treatment. I just feel that I had trouble getting enough information” (Participant 3).* Some of the participants spoke of having a hard time accessing their health information for various reasons. *“I finally see my pathology report because when I saw my family doctor he kind of implied that the pathology report was too many pages to print” (Participant 1).*

Some of the women did not know which information was relevant and felt overwhelmed by all the information they were given. *“They handed you a paper on all the thousand side effects of this particular drug and if that’s not on there, I’m just going to assume that its something else or normal” (Participant 1).* Another participant said, *“I was given information on the drugs I was taking but I wish someone would have told me what neuropathy is, what it feels like at the beginning stages cause mine got really quite severe” (Participant 2).* Another participant said *“It’s really overwhelming, all the information. Like, have you seen the binder they give? Yeah, which is good, you know, it’s good cause there’s lots of stuff in there but it’s a little much” (Participant 7).*

A lot of the women spoke of receiving information from multiple sources. One participant spoke of receiving support from the therapists at the lymphedema clinic, including mental health support and advice on other aspects of care. Another participant spoke of her

daughter finding information for her, that was not easy to access.

*She [daughter] ran around the Pasqua (hospital) looking for meetings that might be coming up, information that I should know. She told me about a couple meetings at Wascana that she had found that you know, might be useful after you've had a mastectomy. So she ran around and found this information, nowhere did anyone ever say that, for example, lymphedema might be an issue. So that, to me, was an oversight. (Participant 3)*

#### **4.5.4 Access to support**

Most women felt there was a lack of access to support throughout diagnosis, treatment, and post-care. The professional supports were often individually driven. One participant said the only mental health support she received was her family physician offering her antidepressants. One participant was actively seeing a psychologist before her cancer diagnosis, and she felt that as this psychologist was the only one in the area, had she not already been referred, she would have had no formal support locally. Some felt they may have been able to access support if they had tried. *"If I need it, I probably could have phoned"* (Participant 1). This participant suggested having formal support sooner in the cancer trajectory would have been beneficial.

*Those are probably the scariest days of your life so the liaison or coordinator or whatever should be assigned as soon as my doctor tells me in my little hometown, you have breast cancer, there's the number for the social worker and be in touch. Because it's a really yucky time and it was a little bit too late to have them.*

Others sought or created informal supports. One woman joined a group through the Canadian Cancer Society that matched survivors with patients currently undergoing treatment. The participant felt this was very beneficial and was also convenient as the service was provided

by phone. However, she found this opportunity herself, as it was not provided by the health region or the cancer centre. One woman stated, *“So really, in rural Saskatchewan, unless you know of a group or have family there isn’t too much support”* (Participant 3). One of the participants started a support group locally after she found it was needed. Another participant in a different rural area spoke of attending a support group that was discontinued recently. She spoke of the benefit she felt having it at the time of her treatment and that she felt sympathy for those that would no longer be able to access this support.

Some of the participants spoke of receiving support from survivors and from the community. *“When I was diagnosed I had a lot of support and I had women who had walked my road already who approached me”* (Participant 1). A different participant said, *“I had a few friends who had been through similar experiences, so that was the best support”* (Participant 7). Another participant explained that a group in her community made quilts for people in the community diagnosed with cancer and they had reached out to her. One participant spoke of receiving unsolicited advice from a nurse who was also a cancer survivor regarding natural cancer treatments.

Another woman said that she did not feel that the support would be the same in the city. *“We kind of all know each other, even if we don’t know each other well we know each other by name. Whereas in the city, would you know anybody like to just randomly phone them”* (Participant 1). Another participant said, *“We kind of have our own little clique in our community too, where we look out for each other”* (Participant 4).

Additionally, there is a significant pattern of digitally enabled access. Aside from the telehealth aspects (discussed previously), all of the women spoke of using social media, in particular Facebook, for support. All of the women who had a diagnosis of breast cancer

belonged to the same group on Facebook. They all spoke of the benefits of this group and how they felt it improved their quality of life while undergoing treatment into their survivorship or palliative experiences. One participant spoke of how talking about similar experiences was beneficial. One of the women said *“I have to say, these women are so positive and supportive to each other. It’s quite amazing”* (Participant 7) about the Facebook support group. Another of the women said, *“I had done some research because I belonged to a couple of online support groups that are huge fountains of information”* (Participant 5). This participant also spoke of receiving emotional support from the Facebook group *“Just hugely supportive. You know, if anything happens that upsets you or anything they’re there.”*

Gaps in the access were further discussed by the participants. For example, they expressed disappointment in being unable to attend some of the in-person events put on by the Facebook group they were part of. *“I have never been there on the right day to be able to join them, but wouldn’t it be nice if I lived in the city and I could have accessed the lymphedema swimming group or met with like folks”* (Participant 6). Another participant said, when speaking about the in-person events, *“The stuff is there, its just that we live far away so how do you get in on it”* (Participant 1). Another participant said, *“What breaks my heart is I see how much more they can do in the city”* (Participant 4). One of the women spoke of *“making the choice”* to go to some of the events in Regina that she felt were applicable to her (Participant 6). She said, although it was worth it, it was sometimes tiresome and very time consuming to go. One of the participants with a palliative diagnosis spoke of the benefits of online support specific to her terminal diagnosis. The participant felt that the diagnosis made many friends and family uncomfortable, so the support she received from others with a palliative diagnosis was very beneficial. She spoke of many situations that were *“typical”* of long-term cancer patients with

stage four cancers, information that she had found on the Facebook group she was part of that was specifically for those with stage four cancer.

The lack of support for family, particularly spouses and children, was noted in many of the interviews. One of the women spoke of the lack of support in regard to sexual health for her and her husband. She told of having to find her own resources for this, which included travelling to Regina for a presentation. Many of the participants spoke of the lack of support for their families. *“I would say there is maybe a gap in support for [husband]. Like they do have social workers there but it’s out of town. It was really hard on [husband], really, really hard on him and I can imagine it would be hard on people’s kids too. It was hard on my mom too”*

(Participant 6). One of the participants felt that there would be more options for spouses to find support if they lived in a bigger center. Another participant spoke of the lack of access to help with everyday life during treatment. She spoke of how having babysitting services or cleaning services would have been of benefit, but that these services were not available to her in her area.

#### ***4.5.5 Access to services***

Most of the participants were satisfied with the care they received at the ABCC. One participant said she was satisfied with the care as a whole but was quite frustrated with the lack of consistency in the care provider. She stated that she had had many different oncologists. Another participant spoke of feeling that she received specialist care too late in her treatment. *“Why was I seeing this oncologist so far down the road?” (Which participant?)*

One of the participants spoke of the logistics of having her bloodwork done pre chemotherapy, especially when her treatments were on Mondays.

*When you live in a rural area, having treatments on Mondays can be difficult.*

*They would prefer you to have your bloodwork done 24 to 48 hours prior to your*

*treatment. So, for me to have it done during that timeframe, I would go to outpatients at our hospital, find out when or leave my name, cause if the lab gets called in then they would call me and they would do my bloodwork at the same time, cause they don't have lab on the weekends. (Participant 2)*

This participant also spoke of the issue of having blood drawn from her PORT at her local hospital *"In order to access my port, I have to go to outpatients, a nurse has to access it, so the nurse and lab technician come together."* She said that she had been having her blood drawn from her arm as a peripheral draw instead of through her PORT because of the time it took and the resources she felt it took to draw blood from her PORT.

Another example to support this theme is reflected by one participant's statement that when she changed her treatment both her local oncology program and the cancer clinic in Regina were calling her and saying different things. She further stated that there was more availability of supportive care when having treatment in Regina and she was forced to wait an extra day to have a chemotherapy bottle removed due to lack of staff on weekends at the local hospital.

Some of the participants spoke of feeling that their local physicians were not always knowledgeable in oncological care. One participant said, *"The doctor that I saw, I don't think he really has a grasp of how you're supposed to treat cancer"* (Participant 4). This was after the participant had gone to her general physician with an infection, and after calling the cancer clinic herself, realized she should have had blood work done and more monitoring due to being on chemotherapy. Conversely, another participant felt that when she sought out care locally, her concerns were always taken seriously, and treatment was quick.

One of the participants spoke of the difference in nursing practices she noticed between urban and rural care. She said that she felt the nurses working in urban centres were more rushed

and felt they were concentrating on their charting more than treating the patient.

Some of the participants spoke of knowing health care providers outside of the hospital environment and the benefits of this. One participant had a nurse assist her with an at home treatment, because she knew her outside of the hospital. One of the participants also spoke of receiving care from primarily nurses at the hospital as the doctors were in clinic and only see non-urgent patients after their clinic hours. Another participant, who had a young child during her treatment, spoke of the nurses helping her with her child during treatment and how supported she felt because of this attention. One participant spoke of using the emergency department as a walk-in clinic/ambulatory care clinic as there were no options for walk-in clinics. She stated, “*I know your brain is going ‘Don’t use the ER for unnecessary things’ but that’s what you have to do*” (Participant 6).

#### **4.6 Summary**

Using the ID methodology, themes and subthemes, including the participants own words, are described and discussed. The participants shared their feelings through the cancer trajectory, commonly anxiety and worry, loneliness, humour, and gratitude and hope. All of the participants spoke of the worry they felt waiting for their results after initial testing, as well as the fear they felt of cancer recurrence or progression. The women all expressed gratitude towards the health care providers they had encountered. The women in this study showed resiliency and self-efficacy throughout their cancer diagnosis and treatments. This was expressed in many different ways, such as “doing what needs to be done”, advocating for themselves within the healthcare system, and also finding solutions for problems outside of the healthcare system. All of the participants expressed concern for others, and some spoke of passing it on, referring to the support they had received during their diagnosis and treatment. Receiving information at the

wrong times and waiting for services were common themes among the participants. The difficulty in accessing services and support were common experiences for the participants. Travel was required for all participants at some point. Travel alternatives, such as telehealth, were generally very appreciated but some felt underutilized. Many of the participants felt it was difficult to access enough information related to their diagnosis and treatment. But, relating back to the resiliency of these participants, most advocated for themselves or found a way to find it. All of the participants used social media for support and information, and all expressed the benefits of using it. Many of the participants spoke of the lack of access to psychological support and logistical problems during treatment. However, some of the participants also spoke of the support they received from the community.



## **CHAPTER FIVE**

### **Discussion of Results**

#### **5.1 Overview**

This chapter will discuss and interpret the results of the study as they relate to the literature. The research question guiding this study, what are the perceptions of women living with a cancer diagnosis in rural Southern Saskatchewan regarding their met and unmet care needs, was answered by conducting in depth interviews and interpreting the findings from the interviews. Our decision to define rural in a specific manner was intentional as we hoped to embrace women in areas that were less urban linked (further from a larger centre). By clearly defining rural for our purposes, we hoped to make our findings more comparable. Although each participant's experience was unique, similarities were found within the interviews. In this chapter feelings, specifically fear and anxiety in regard to recurrence or progression, are described. The resiliency of the participants and of rural women in general are discussed. Access to services and supports, as well as accessing information and receiving information at the correct time are all discussed and situated in the literature.

#### **5.2 Feelings during the Cancer Continuum**

All participants in this study expressed feeling anxious or worried at some point in their cancer care. Most commonly, this was expressed in the fear of recurrence or progression of cancer, which is echoed by Hubbard et al. (2015) where participants most prevalent unmet care needs were 'being informed about cancer in remission' and 'fears about cancer spreading'. Rural cancer participants in another study also described fearing recurrence and feeling the loss of their normal (Fuchsia Howard et al., 2014). Loughery and Woodgate (2019) found that unmet needs in the psychological domain were often due to a perceived loss of control over the illness

experience, which aligns with the findings of this study. Although the feelings described by the participants in this study may be generalizable to women with cancer in urban areas (Hubbard et al., 2015; Miedema et al., 2004), Burris and Andrykowski (2010) found that cancer survivors in rural areas had more anxiety and depression than their urban counterparts and Salehi et al. (2019) found that rurality was a risk factor for lower mental health outcomes and higher levels of distress.

The participants in this study described the lack of available psychological resources, which is also found in the literature. There is a lack of social workers and mental healthcare professionals in rural areas and those that are available locally are not often specific to cancer care (Charlton et al., 2015; Salehi et al., 2019). Family physicians in one study also described having a harder time finding mental health supports for their rural oncology patients (Charlton et al., 2015). Travel and distance have been noted as being a barrier to receiving emotional support services for rural people with cancer (Fuchia Howard et al., 2014; Hubbard et al., 2015). Support groups have been described as valuable in the literature, but often are not available, usually due to the need to travel, as mentioned above (Haigh et al., 2019; Hubbard et al., 2015). The lack of availability of these psychological supports may contribute to lower mental health status in rural cancer patients and unmet needs in the psychological domain (Coyne et al., 2019; Salehi et al., 2019). As is clear in this study, as well as the literature, community-based supports for mental and emotional health are needed at the local level for cancer patients in rural areas (Salehi et al., 2019). Some studies describe the benefits of telemedicine or e-health in regard to meeting psychological needs, as the burden of travel would be removed (Coyne et al., 2019; Hubbard et al.); however, information about these services should be readily available, as some rural participants with cancer in one study were not aware of such services (Fuchsia Howard et al.,

2014).

### **5.3 Resiliency**

There was a theme of resiliency and self-efficacy among the interviews, although the women did not use these terms. This was expressed as “doing what needs to be done”, “moving on” or “powering through”. Participants in a study by Hegney et al. (2007) described resiliency as “the ability to ‘bounce back’” (p. 6). Resilient people were also described as being positive, resourceful, adaptable, and tough. It was also noted in this study that taking action and problem solving were seen as characteristics of resiliency (Hegney et al., 2007). The characteristics described align with the characteristics of the women in this study. Other components of resiliency described in the literature are determination and perseverance, which coincide with the findings of resilience in the women in this study (Buikstra et al., 2015). Worth mentioning is the study by Buikstra et al. (2015) which investigated both resilience in individuals as well as community resilience. “Resilience as a theoretical construct has become a central narrative of rural development discourse internationally and in Canada” (Peters, 2019, p. 41), which has contributed to the urban-normative or gold standard while failing to acknowledge the unique strengths of rural communities and residents (Peters, 2019; Rickards, 2011). This was not discussed in this research study but could be explored in future research. The participants spoke of advocating for better care throughout their cancer journey. In one study comparing rural and urban cancer survivors, rural cancer survivors were “especially committed to improving health care in their communities” (McNulty & Nail, 2015, p. 288).

In the literature, rural women with cancer have been described as strong, self-sufficient, empowered, resilient, hardy, and self-reliant (Butow et al., 2014; Rogers-Clark, 2002). Just as Rogers-Clark (2002) found, women in the current study never portrayed themselves as victims of

the burdens from rural living and did not see themselves ‘overall’ as disadvantaged by their rural context. Gerrard and Woodland (2012) describe how rural women in Saskatchewan have demonstrated stress resiliency to cope with unexpected or long-term stress such as experienced by the participants in the current study. Similarities were also found with findings of the Leipert (2006) study where rural women with cancer were active in making decisions about health care services and that participants would actively seek out information and support.

#### **5.4 Access**

In the past, it has been found that rural and urban women with cancer have different needs. This has been attributed to distance from care and lack of sufficient health providers who are knowledgeable about local cancer services (Fuchsia Howard et al., 2014; Lawrensen et al., 2016). However, in line with the findings of Mahling et al. (2020), accessibility is a persistent theme which reached beyond distance to include access to “information, to personnel, and to care’ (p. 8). Fuchsia Howard et al. (2014) found that local physicians were not always able to answer questions for rural breast cancer survivors/or in any phase of curative or palliative needs. Many of the participants thought this was due to lack of cancer specific knowledge of physicians. This thinking was echoed by many of the women in this study. The participants, who were people living in rural areas in British Columbia who had been diagnosed with cancer, in a study by Fuchsia Howard et al. (2014) also described difficulty in receiving accurate, timely information. The participants expressed feeling information was either not given, specifically about long term side effects, or was too general from their general practitioners. The women interviewed in our study echoed this and felt the general practitioners in their local community were not always aware of the best treatment for cancer patients. Interestingly, all of the women in the study who spoke about this knowledge gap were forgiving. The women expressed that

they felt the physicians were doing the best they could under the pressures of lack of resources and having to know about all different diseases. Women with breast cancer living in rural areas in another study described not having access to qualified health professional, even in non-cancer settings, and having limited rural emergency services when needed (Loughery & Woodgate, 2019).

All participants were required to travel for some or all of their cancer treatment, but to these participants, it seemed it was just a fact of life. However, the participants did describe some of the burdens of travelling for cancer treatment and follow up, which were also discussed in the literature. Travel was the most common burden experienced at the system level in rural cancer care in one study (Salehi et al., 2019), and rural participants with cancer in another study described the burden of travel not ending with treatment, as they were required to continue to travel for follow up care (Charlton et al., 2015). The worsening of physical symptoms, including pain and fatigue, is found in many studies among rural cancer patients who had to travel for treatment or follow up (Coyne et al., 2019; Loughery & Woodgate, 2019; Loughery & Woodgate, 2015). It has also been found that travel may increase worry and anxiety in rural cancer patients (Loughery & Woodgate, 2019). The burden of asking family and friends to assist with travel and accommodations was described by some participants and has been discussed in some of the literature (Haigh et al., 2019).

The cost of travel, including out of pocket costs from accommodations, parking, and fuel, were mentioned by the participants and have also been cited in the literature. This financial burden is an added challenge to rural cancer patients and their families after diagnosis (Coyne et al., 2019). The cost of travel is a major burden, not only to treatment but also for follow up care such as rehabilitation (Fuchsia Howard et al., 2014; Loughery & Woodgate, 2015). In one

Canadian study, rural residents reported considering out-of-pocket costs during their cancer care journey more frequently than urban patients (Matthews et al., 2009). It was noted in the literature that such costs would not be a concern for cancer patients living in urban areas (McNulty & Nail, 2015).

Telehealth solutions have been found to be feasible and acceptable in the rural oncology setting and most of the participants in this study found this service beneficial (Charlton et al., 2015). The use of this type of technology has also been shown to improve the rural health experience when used by general practitioners to support treatment of rural patients with cancer (Hubbard et al, 2014).

#### ***5.4.1 Social media***

All of the participants in this study discussed the use of social media. The women described sharing their experiences, getting information from others in the same situation or who had already been through treatment and feeling emotionally supported by others in the social media groups they were part of. The use of social media to meet informational and emotional support needs described by the women in this study is also found in the literature. Research has found that patients and their families find valuable emotional support from social media groups, and that participating in some social media groups can decrease anxiety as it increases perceived knowledge (Attai et al., 2015; Gentile et al., 2018; Harkin et al., 2017; Moorhead et al., 2013). Participants in some studies have expressed feeling validated and empowered. They have said that social media messages increase their self-esteem, and that they felt a greater sense of control over their own cancer experience (Griffiths et al., 2012; Harkin et al., 2017). The research has shown participants find sharing their story very beneficial. One of the participants in this study told of not feeling comfortable expressing her emotions to her family and found a lot of value in

being able to express her concerns with the online group she was a part of. This experience is congruent with findings in one study, in that most participants expressed feeling that their family and friends did not understand their new life after cancer diagnosis. These participants found that the use of social media addressed this concern (Harkin et al., 2017).

Studies involving social media use in health care have found that the platform can address unmet informational needs (Griffiths et al., 2012; Harkin et al., 2017). Participants in the literature have found it helpful knowing what to expect at different stages of the cancer trajectory and being able to understand some health care terminology and concepts, knowledge that was gained by social media. Some of the participants in this study told of only looking at the information, not always interacting. In one study, this is referred to as “lurking”, and it was found to meet a lot of users informational needs. Social media can provide a tool for patients to self-manage their own cancer care in certain aspects, which has been shown to improve emotional distress and enhance knowledge of the patient’s condition. As discussed in the results of this study, the women in this study were found to all be resilient with a high degree of self-efficacy, so social media may be especially important for these participants to be able to manage their own condition (Harkin et al., 2017)

Another benefit of social media use for support is the ease in which patients can access the information. People can access information from their own home, when it is convenient for them (Griffiths et al., 2012; Moorhead et al., 2013). Traditional methods of information delivery usually involve a large amount of information at one point in time, a concept discussed in many of the interviews in this study. Social media use can provide an opportunity for those with cancer to learn information over time, rather than all at once (Harkin et al., 2017). Although the literature was not specific to rural participants, inferences could be made of the benefit of social

media use to rural residents with cancer, as expressed by the participant's experience in this study, and that participants do not have to travel for emotional support and to meet informational needs.

## **5.5 Information Needs**

Lack of access to cancer care information and receiving information at the incorrect time was a common concern among all participants and was a common finding in the literature. Gray et al. (2004) found that women with breast cancer living in rural areas often found it difficult to access information locally. Loughery & Woodgate (2015) found that many rural cancer patients do not have access to cancer specific information when it is needed, while Coyne et al. (2019) described the concern for rural cancer patients finding appropriate information. Charlton et al. (2015) also found that rural cancer patients had unmet informational needs. The participants in this study spoke of being overwhelmed by the information given to them before starting treatment. Some of the participants spoke of the need for information before it was given, particularly in the period between diagnosis and surgery, and many of the participants described information not always being relevant. Rural general providers were found to have limited knowledge about cancer specific problems (Loughery & Woodgate, 2019). Many participants in one study found that they did not have enough information about the benefits and side effects of treatment, and that they were not given information on the total overview of their care (Hubbard et al., 2015). A study by Loughery & Woodgate (2019) found that participants have found information from a variety of health care providers in many settings. This was echoed in this study. However, in the study by Mahling et al. (2020), rural community members felt that larger social networks contribute to more access to health service knowledge. This was not directly explored in the current study.



## **CHAPTER SIX**

### **Implications and Recommendations**

#### **6.1 Overview**

This chapter will cover implications for nursing practice, education, research, and policy. Nurse navigators and the use of online resources to meet supportive care needs are also discussed.

#### **6.2 Implications for Nursing Practice**

Nurses working in oncology, in both rural areas and urban centers, need to be aware of the potential barriers to care for rural oncology patients. For nurses working in urban cancer centers, an awareness of the barriers rural cancer patients may face could lead to actions by nurses to lessen these burdens, such as more appropriate scheduling or patient education that is specific to rural patients. The participants in this study expressed gratitude for the urban cancer centre staff when they were able to efficiently schedule appointments or coordinate services to be at the same time. Urban oncology nurses should also be aware of the difference in services provided in rural areas when they are recommending care options, such as emotional support or finding information.

Nurses working in rural areas are often well versed in many healthcare situations, as well as other areas of care such as social (Jackman et al., 2010). Nurses working in rural areas should be afforded education so that they can meet cancer patients needs specifically. For some, the most important aspect of this would be being aware of, and directing patients to, the resources that are available. The participants in this study all expressed that they did not receive the information they needed to be comfortable with their care. Nurses can bridge this gap.

Nurses working with cancer patients living in rural areas should be attentive to the needs

of patients outside the physical needs. In this study, rural women with cancer expressed unmet needs in all domains. Rural nurses should note that emotional and psychological support may not be available to the patients they are seeing and find resources to address this.

Rural nurses should be aware of the powerful nature of the patient story. Valuable knowledge was gained from this study of rural patients voices and nurses could use this knowledge to enhance their care for these patients.

### **6.3 Implications for Nursing Research**

The women who participated in this study took responsibility of their care when possible and were all very aware of their own health needs. This should be taken into consideration when developing additional programming for this population, such as oncology specific services closer to rural communities, and the potential for more self-directed online education.

There is an opportunity for further research in the use of online resources, specifically social media, in addressing emotional and informational needs of rural women with cancer. From a healthcare provider's view, the popular use of social media could be an opportunity for further research, such as a national registry or other large scale research study that may be less expensive and easier to organize than some more conventional research methods (Prasad, 2013).

### **6.4 Implications for Nursing Education**

According to MacLeod et al. (2004), there is little in education that prepares nurses for the complicated and intricate practice of rural health nursing. Due to the lack of human and specialty resources often found in rural areas, nurses working in these areas should be taught to be better navigators through the cancer care system. The recommendation for nurse navigators is discussed below. Nurses should also be taught the difference between urban and rural healthcare and how this affects oncology patients.

## **6.5 Implications for Policy and Administration**

Rural nurses and rural healthcare are often governed by policies that are more aligned with urban care (MacLeod et al., 2004). The voice of rural oncology patients can be easily lost in policy making. A town hall forum would provide an opportunity for rural cancer patients to have a voice and discuss priorities for the specific rural area in which they live. Etchegary et al. (2017) successfully engaged community members using this town hall format and the findings provided a starting point for interventions and policy. There is also a need to evaluate current interventions and programming that is in place in Saskatchewan for rural women with cancer.

## **6.6 Nurse Navigators**

Participants in this study expressed frustration in finding information, not knowing what to expect regarding treatments and side effects, and not feeling adequately supported in many domains of care within their rural communities. Nurse navigators would be potentially of benefit in addressing these concerns. The CANO has published a position statements in support of the nurse navigator (CANO, 2020). The benefits of nurse navigators across settings have been documented. Oncology patients assigned a nurse navigator were significantly more satisfied with the oncology care they received than those who did not have a nurse navigator involved in their care (Loiselle et al. 2020; Yackzan et al., 2019). Coyne et al. (2019) found that women with breast cancer who received the services of a nurse navigator felt they understood the information given to them better and felt more supported in general. Nurse navigators have also been shown to decrease inpatient oncology patients' distress scores (Swanson & Koch, 2010). The benefits of nurse navigator use in the rural setting include connecting patients with needed resources, lowering emergency room use, facilitating the ability to die in their preferred place of death, increasing health literacy, and improving access to health services and equity in health services. Nurse navigators that are specific to both oncology and rural patients could be beneficial in addressing many of the concerns expressed by the women in the current study. None of the

women in this study said they had worked with a navigator. Two of the participants felt that a health care provider specifically assigned to them in the time between diagnosis and treatment would have been very valuable,

## **6.7 Meeting Supportive Care Needs Online**

All of the women interviewed in this study found support through social media groups. Harkin et al. (2017) discuss the influence social media can have on the patient relationship with their health care providers. In this study, participants spoke of being aware of the limited time they had with their health care provider and that if they had more knowledge going into these appointments that they would be able to participate more in the discussion. The use of social media should not be discounted as a means to provide information to rural cancer patients. Patients are already using social media to access health information and are finding it beneficial. One concern with the use of social media is the accuracy of health information available. Nurses could increase their role by increasing health literacy and appraisal tools for those using social media and their families (Harkin et al., 2017).

Internet delivered cognitive behaviour therapy has shown to be effective in decreasing cancer survivors' mood disturbances and fear of recurrence, as well as increasing the quality of life of participants (Dirkse et al., 2019). The accessibility of Internet delivered cognitive behaviour therapy ICBT would be very beneficial to rural oncology patients, as the participants in this study expressed having to travel for this care. Another potential solution to participant concerns of difficulty accessing timely information would be to tailor information to address various changing needs at different time points through cancer care. The use of an interactive multimedia program, as suggested by Skalla et al. (2004), would address the concerns found in this study as "Programs can engage patients in an active learning process that allows them to control the amount and type of information that is presented, the pace at which it is presented, and the format in

which it is presented” (p. 318). This technology would potentially address many of the barriers of living in a rural area and accessing information.

## **CHAPTER SEVEN**

### **Conclusion**

#### **7.1 Overview**

This chapter will discuss the limitations of the study and strategies for knowledge exchange, future directions and conclusions.

#### **7.2 Limitations and Strengths**

The richness of the data collected from the interview may have been affected by the researcher's inexperience with interviewing participants. There was also difficulty with recruitment using recruitment posters at the ABBC and the Cancer Patient Lodge. Recruitment was primarily done by the snowballing technique. The researcher acknowledges the limitations of this sampling technique, and that the perspectives of women who were not reached by this technique were not represented, including those without access to social media, as well as those who are not as forthcoming with wanting to share their experiences. Another limitation of the study is that only four participants agreed to a follow up phone call interview. This meant that the researcher was not able to discuss some of the ideas from the first interview or clarify meaning of some of the concepts with some of the participants.

The researcher had a strong link to southern Saskatchewan and was familiar with the context and culture of the area. This, along with the researchers experience at the Allan Blair Cancer Centre, gave her credibility with this participant group. The researcher's thesis committee provided a strength to this study as the members had a wide range of expertise. As mentioned above, the similarities that exist between other areas of rural Saskatchewan provide an opportunity to extend the learnings from this research project.

### **7.3 Knowledge Translation**

The study findings will be presented to the staff at the ABCC and the Cancer Patient Lodge in Regina, Saskatchewan. Abstracts will be submitted for appropriate provincial and national conferences. An article from this study will be submitted for publication in a relevant peer-reviewed journal. All of the participants in this study indicated they would like a summary of the findings so a plain language summary of the study will be emailed to the participants at the email they provided.

## 7.4 Conclusions

This research provides further knowledge in the care needs of women living in rural areas diagnosed with cancer. The burden of travel, lack of access to services and support to meet supportive care needs, and difficulty finding information on numerous issues throughout the cancer journey all contribute to the unmet supportive care needs of women living in rural areas in Saskatchewan. Provincial, national, and international literature support these findings.

This study has implications for nursing practice, policy, and research. Nurses practicing in rural areas are in a unique position to meet the needs of cancer patients living in these areas. Understanding the differences in rural living, and the barriers and benefits that come with it is important. Providing resources at appropriate times throughout the care trajectory, or knowing where to find resources if needed, would assist in meeting the unmet needs of this population. Policies must move toward a more rural focus, specific to the communities the policies guide care for, versus urban-centric policies implemented throughout the province.

The resilient nature of the rural women in this study should also be considered. The voices of these women were so powerful when telling their stories of advocating for different treatment. The women must be viewed in the context of their strengths and insights – their lived experiences are the imperative to our understandings. The importance of taking care of the family and community, and the self-efficacy of these women to find resources themselves should be understood and nurtured when implementing interventions specific to rural cancer patients.



## REFERENCES

- Ahmed, S., & Shahid, R. K. (2012). Disparity in cancer care: A Canadian perspective. *Current Oncology*, 19(6), e376-82 <https://doi.org/10.3747/co.19.1177>
- Attai, D., Cowher, M., Al-Hamadani, M., Schoger, J., Staley, A., & Landercasper, J. (2015). Twitter social media is an effective tool for breast cancer patient education and support: Patient-reported outcomes by survey. *Journal of Medical Internet Research*, 17(7). <https://doi.org/10.2196/jmir.4721>
- Brenner, D. R., Weir, H. K., Demers, A. A., Ellison, L. F., Louzado, C., Shaw, A., Turner, D., Woods, R. R., & Smith, L. M. (2020). Projected estimates of cancer in Canada in 2020. *Canadian Medical Association Journal*, 192 (9), 199-205. <https://doi.org/10.1503/cmaj.191292>
- Buikstra, E., Ross, H., King, C., Baker, P., Hegney, D., McLachlan, K., & Rogers-Clark, C. (2010). The components of resilience—Perceptions of an Australian rural community. *Journal of Community Psychology*, 38(8), 975-991. <https://doi.org.cyber.usask.ca/10.1002/jcop.20409>
- Burris, J.L., & Andrykowski, M. (2010). Disparities in mental health between rural and non-rural cancer survivors: A preliminary study. *Psycho-Oncology*, 19:637-45. <https://doi.org/10.1002/pon.1600>
- Butow, P.N., Phillips, F., Schweder, J., White, K., Underhill, C., & Goldstein, D. (2012). Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: A systematic review. *Supportive Care Needs*, 1, 1-22. <http://doi.org/0.1007/s00520-011-1270-1>

Canadian Cancer Society. (2016) *Right to Care: Palliative Care for all Canadians*.

<https://www.cancer.ca/~media/cancer.ca/CW/get%20involved/take%20action/Palliative-care-report-2016-EN.pdf?la=en>

Canadian Cancer Statistics Advisory Committee. (2019) *Canadian Cancer Statistics 2019*.

<https://www.cancer.ca/~media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2019-EN.pdf?la=en>

Canadian Institute for Health Information. (2006). *How Healthy are Rural Canadians? An Assessment of Their Health Status and Health Determinants*. Ottawa, ON: CIHI.

Canadian Institute for Health Information. (2018). *In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality — A Focus on Age, Sex, Gender, Income, Education and Geographic Location*. Ottawa, ON: CIHI

Canadian Association of Nurses in Oncology. (2020). *Patient Navigator in Cancer Care-A Specialized Oncology Nurse Role that Contributes to High Quality, Person-Centered Care Experiences and Clinical Efficiencies*. [https://cdn.ymaws.com/www.cano-acio.ca/resource/resmgr/position\\_statements/Patient\\_Navigation\\_2020\\_EN.pdf](https://cdn.ymaws.com/www.cano-acio.ca/resource/resmgr/position_statements/Patient_Navigation_2020_EN.pdf)

Case, M. (2011). Oncology nurse navigator: Ensuring safe passage. *Clinical Journal of Oncology Nursing*, 15(1), 33-40.

<http://cyber.usask.ca/login?url=https://www.proquest.com/scholarly-journals/oncology-nurse-navigator-ensuring-safe-passage/docview/850438090/se-2?accountid=14739>

Charlton, M., Schlichting, J., Chioreso, C., Ward, M., & Vikas, P. (2015). Challenges of rural cancer care in the United States. *Oncology (08909091)*, 29(9), 633-640.

<https://pubmed.ncbi.nlm.nih.gov/26384798/>

<https://link.gale.com/apps/doc/A429410757/EAIM?u=usaskmain&sid=EAIM&xid=f89edd80>

Chou, W., Hunt, Y., Folkers, A., & Augustson, E. (2011). Cancer survivorship in the age of YouTube and social media: A narrative analysis. *Journal of Medical Internet Research, 13*(1), E7. <https://doi.org/10.2196/jmir.1569>

Coyne, E., Frommolt, V., & Salehi, A. (2019) The experience and challenges of rural persons with cancer and their families, *Collegian, 26*(6), 609-614.  
<https://doi.org/10.1016/j.colegn.2019.10.002>

Decker, K., Demers, A., Chateau, D., Musto, G., Nugent, Z., Lotocki, R., & Harrison, M. (2009). Papanicolaou test utilization and frequency of screening opportunities among women diagnosed with cervical cancer. *Open Medicine: A Peer-reviewed, Independent, Open-access Journal, 3*(3), E140-7. <https://www.ncbi.nlm.nih.gov/cyber.usask.ca/pmc/articles/PMC3090124/>

Depke, J., Boreen, A., & Onitilo, A. (2015). Navigating the needs of rural women with breast cancer: A breast care program. *Clinical Medicine, & Research, 13*(3), 149-155.  
<https://doi.org/10.3121/cmr.2015.1260>

Dirkse, D., Hadjistavropoulos, H., Schneider, N., Alberts, E., Karin, L., Titov, B., & Dear. (2019). Making Internet-delivered cognitive behaviour therapy scalable for cancer survivors: A randomized non-inferiority trial of self-guided and technician-guided therapy. *Journal of Cancer Survivorship, 14*(2), 211-225. <https://doi.org/10.1007/s11764-019-00810-9>

Drury, V.B. & Inma, C. (2010). Exploring patient experiences of cancer services in regional

Australia. *Cancer Nursing*, 33(1), E25-31.

<https://doi.org/10.1097/NCC.0b013e3181af5675>

Duggleby, W.D., Penz, K.L., Goodridge, D.M., Wilson, D.M., Leipert, B.D., Berry, P.H., ....

Justice, C.J. (2010). The transition experience of rural older persons with advanced cancer and their families: A grounded theory study. *BMC Palliative Care*, 9(5), 1–9.

<https://doi.org/10.1186/1472-684x-9-5>

Duggleby, W., Penz, K., Leipert, B., Wilson, D., Goodridge, D., & Williams, A. (2011). 'I am

part of the community but...' The changing context of rural living for persons with advanced cancer and their families. *Rural and Remote Health*, 11(3), 1733.

<https://doi.org/10.22605/RRH1733>

Etchegary, H. E., Bishop, L., Street, C., Humphries, D., Vat, L., Barrett, B., & Aubrey-Bassler,

K. (2017). Engaging patients in health research: Identifying research priorities through community town halls. *BMC Health Services Research*, 17(1), 192.

<https://doi.org/10.1186/s12913-017-2138-y>

Fletcher, C., Flight, I., Chapman, J., Fennell, K., & Wilson, C. (2017). The information needs of

adult cancer survivors across the cancer continuum: A scoping review. *Patient Education and Counseling*, 100(3), 383-410. <https://doi.org/10.1016/j.pec.2016.10.008>

Fitch, M.I., Porter, H.B., & Page, B.D. (2009). *Supportive care framework: A foundation for person-centred care*. Pembroke, ON: Pappin Communications.

Fitch, M. I., & Steele, R. (2010). Supportive care needs of individuals with lung cancer.

*Oncology Nursing Journal*, 20(1), 15-22. <https://doi.org/10.5737/1181912x2011522>

Forte, T., Porter, G., Rahal, R., DeCaria, K., Niu, J., & Bryant, H. (2014). Geographic disparities

- in surgery for breast and rectal cancer in Canada. *Current Oncology*, 21(2), 97–99.  
<http://doi.org/10.3747/co.21.1936>
- Fuchsia, H., Smillie, K., Turnbull, K., Zirul, C., Munroe, D., Ward, A., Tobin, P., Kazanjian, A., & Olson, R. (2014). Access to medical and supportive care for rural and remote cancer survivors in northern British Columbia. *Journal of Rural Health*, 30(3), 311-321.  
<https://doi-org.cyber.usask.ca/10.1111/jrh.12064>
- Gage-Bouchard, E., LaValley, A., Warunek, S., Beaupin, M., & Mollica, L. (2018). Is cancer information exchanged on social media scientifically accurate? *Journal of Cancer Education*, 33(6), 1328-1332. <https://doi.org/10.1200/JCO.2017.35.5suppl.186>
- Gentile, D., Markham, M.J., & Eaton, T. (2018). Patients with cancer and social media: Harness benefits, avoid drawbacks. *Journal of Oncology Practice*, 14(12): 731-736.
- Gerrard, N. & Woodland, A. (2012). Gender politics and rural women: Barriers to and strategies for enhancing resiliency. In B. Leipert, B. Leach, & W.E. Thurston (eds). *Rural Women's Health*, University of Toronto Press. <https://doi.org/10.3138/9781442662513-016>
- George, M., Ngo, P., & Prawira, A. (2014). Rural oncology: Overcoming the tyranny of distance for improved cancer care. *Journal of Oncology Practice/American Society of Clinical Oncology*, 10(3), e146-9. <https://doi.org/10.1200/JOP.2013.001228>
- Gilbertson-White, S., Yeung, C., & Wickersham, K. (2019). "Just Living With Them": Symptom management experiences of rural residents with advanced cancer. *Oncology Nursing Forum*, 46(5), 531-542. <https://doi.org/10.1188/19.ONF.531-542>
- Giuliani, M. E., Milne, R. A., Puts, M., Sampson, L.R., Kwan, J., Le, L., ... Jones J. (2016). The

- prevalence and nature of supportive care needs in lung cancer patients. *Current Oncology (Toronto, Ont.)*, 23(4), 258-65. <https://doi.org/10.3747/co.23.3012>
- Goodridge, D., & Duggleby, W. (2010). Using a quality framework to assess rural palliative care. *Journal of Palliative Care*, 26(3), 141-150.  
<http://cyber.usask.ca/login?url=https://www.proquest.com/scholarly-journals/using-quality-framework-assess-rural-palliative/docview/756979056/se-2?accountid=14739>
- Gray, R.E., James, P., Manthorne, J., Gould, J., & Fitch, M.I. (2004). A consultation with Canadian rural women with breast cancer. *Health Expectations*, 7, 44–50.  
<https://doi.org/10.1046/j.1369-6513.2003.00248.x>
- Griffiths, F., Cave, J., Boardman, F., Ren, J., Pawlikowska, T., Ball, R., Clarke, A., & Cohen, A. (2012). Social networks – The future for health care delivery. *Social Science Medicine*, 75(12), 2233-2241. <https://doi.org/10.1016/j.socscimed.2012.08.023>
- Grimison, P., Phillips, F., Butow, P., White, K., Yip, D., Sardelic, F., ... Goldstein, D. (2013). Are visiting oncologists enough? A qualitative study of the needs of Australian rural and regional cancer patients, carers and health professionals. *Asia-Pacific Journal of Clinical Oncology*, 9(3), 226-238. <https://doi.org/10.1111/ajco.12014>
- Haigh, M. M., Baxi, S., Lyford, M., Cheetham, S., & Thompson, S. C. (2019). Cancer support services: Are they meeting the needs of rural radiotherapy patients? *European Journal of Cancer Care*, 28(1), N.PAG. <https://doi-org.cyber.usask.ca/10.1111/ecc.12904>
- Hall, A., Lynagh, M., Bryant, J., & Sanson-Fisher, R. (2013). Supportive care needs of hematological cancer survivors: A critical review of the literature. *Critical Reviews in Oncology / Hematology*, 88(1), 102-116. <https://doi.org/10.1016/j.critrevonc.2013.03.008>

- Harkin, L., Beaver, J., Dey, K., & Choong, P. (2017). Navigating cancer using online communities: A grounded theory of survivor and family experiences. *Journal of Cancer Survivorship, 11*(6), 658-669. <https://doi-org/10.1007/s11764-017-0616-1>
- Haq, R., Heus, L., Baker, N., Dastur, D., Leung, F., Leung, E., Li, B., Vu, K., & Parsons, Janet A. (2013). Designing a multifaceted survivorship care plan to meet the information and communication needs of breast cancer patients and their family physicians: Results of a qualitative pilot study. *BMC Medical Informatics and Decision Making, 13*(1), 76. <https://doi-org/10.1186/1472-6947-13-76>
- Hegney, Buikstra, Baker, Rogers-Clark, Pearce, Ross, ... Watson-Luke. (2007). Individual resilience in rural people: A Queensland study, Australia. *Rural and Remote Health, 7*(4), 620. <https://doi.org/10.22605/RRH620>
- Hook, A., Ware, L., Siler, B., & Packard, A. (2012). Breast cancer navigation and patient satisfaction: Exploring a community-based patient navigation model in a rural setting. *Oncology Nursing Forum, 39*(4), 379-385. <https://doi.org/10.1188/12.ONF.379-385>
- Howell, D., Mayo, S., Currie, S., Jones, G., Boyle, M., Hack, T ... Simpson, J. (2012). Psychosocial health care needs assessment of adult cancer patients: A consensus-based guideline. *Supportive Care in Cancer, 20*(12), 3343-3354. <https://doi.org/10.1007/s00520-012-1468-x>
- Hubbard, G., Venning, C., Walker, A., Scanlon, K., & Kyle, R. G. (2015). Supportive care needs of women with breast cancer in rural Scotland. *Supportive Care in Cancer, 23*(6), 1523–1532. <https://doi-org.cyber.usask.ca/10.1007/s00520-014-2501-z>
- Jhaveri, D., Larkins, S., Kelly, J., & Sabesan, S. (2016). Remote chemotherapy supervision

- model for rural cancer care: Perspectives of health professionals. *European Journal of Cancer Care*, 25(1), 93-98. <https://doi.org/10.1111/ecc.12309>
- Kulig, J., Kilpatrick, K., Moffitt, P., & Zimmer, L., (2013). *Rural and Remote Nursing Practice: An Updated Documentary Analysis*. Lethbridge: University of Lethbridge.
- Kulig, J.C., & Williams, A.M. (2012). *Health in rural Canada*. Vancouver: UBC Press.
- Lavergne, M. R., Johnston, G. M., Gao, J., Dummer, T. J. B., & Rheume, D. E. (2011). Variation in the use of palliative radiotherapy at end of life: Examining demographic, clinical, health service, and geographic factors in a population-based study. *Palliative Medicine*, 25(2), 101-110. <https://doi.org/10.1177/0269216310384900>
- Lavis, J.N., & Boyko, J. (2010). *Developing a rural health strategy in Saskatchewan*. Canadian Electronic Library and McMaster Health Forum.
- Lawrenson, R., Lao, C., Elwood, M., Brown, C., Sarfati, D., & Campbell, I. (2016). Urban rural differences in Breast cancer in New Zealand. *International journal of environmental research and public health*, 13(10), 1000. <https://doi.org/10.3390/ijerph13101000>
- Leipert B. (2006). Rural and remote women developing resilience to manage vulnerability. In: Lee H, Winter C, eds. *Rural Nursing: Concepts, Theory and Practice*. 2nd ed. New York, NY: Springer; 2006:79-95.
- Leipert, B. D., Delaney, J. W., Forbes, D., & Forchuk, C. (2011). Canadian rural women's experiences with rural primary health care nurse practitioners. *Online Journal of Rural Nursing & Health Care*, 11(1), 37-53. <https://doi.org/10.14574/ojrnhc.v11i1.8>
- Lengoc, S., French, M., Tyldesley, C. & Olson, R. (2011). Referral patterns of patients for



- palliative radiation therapy in British Columbia: A comparison between northern and urban family physicians. *International Journal of Radiation Oncology, Biology, Physics*, 81(2), S567-S568. <https://doi.org/10.1016/j.ijrobp.2011.06.901>
- Lockie, S., Bottorff, J., Robinson, C., & Pesut, B. (2010). Experiences of rural family caregivers who assist with commuting for palliative care. *Canadian Journal of Nursing Research*, 42(1), 74-91. <https://cjr.archive.mcgill.ca/article/view/2236>
- Loiselle, C. G. , Attieh, S., Cook, E., Tardif, L., Allard, M., Rousseau, C., ... Talbot, D. (2020). The nurse pivot-navigator associated with more positive cancer care experiences and higher patient satisfaction. *Canadian Oncology Nursing Journal*, 30(1), 48-53. <https://doi.org/10.5737/236880763014853>
- Loughery, J., & Woodgate, R. L. (2019). Supportive care experiences of rural women living with breast cancer: An interpretive descriptive qualitative study. *Canadian Oncology Nursing Journal*, 29(3), 170. <https://doi.org/10.5737/23688076293170176>
- Loughery, J. & Woodgate, R. (2015). Supportive care needs of rural individuals living with cancer: A literature review. *Canadian Oncology Nursing Journal/Revue Canadienne de Nursing Oncologique*, 25(2), 157-78. <https://doi.org/10.5737/23688076252157166>
- MacLeod, M. L., Kulig, J. C., Stewart, N. J., Pitblado, J. R., & Knock, M. (2004). The nature of nursing practice in rural and remote Canada: This three-year ongoing study is already revealing that nursing in rural and remote Canada is complex and deserves formal recognition, as well as financial and educational support. *The Canadian Nurse*, 100(6), 27-31. <http://cyber.usask.ca/login?url=https://www.proquest.com/scholarly-journals/nature-nursing-practice-rural-remote-canada-this/docview/232044133/se->

[2?accountid=14739](#)

Mahling, A., LeBlanc, M., & Peters, P.A. (2020). *Report: Rural Resilience and Community Connections in Health: Outcomes of a Community Workshop*. April 24, 2020.

<https://doi.org/10.22215/sdhlab/2020.1>

Matthews, M., West, R., & Buehler, S. (2009). How important are out-of-pocket costs to rural patients' cancer care decisions? *Canadian Journal of Rural Medicine*, 14(2), 54–60.

<http://cyber.usask.ca/login?url=https://www.proquest.com/scholarly-journals/how-important-are-out-pocket-costs-rural-patients/docview/217568290/se-2?accountid=1473>

McConigley, R., Platt, V., Holloway, K., & Smith, J. (2011). Developing a sustainable model of rural cancer care: The western Australian cancer network project. *Australian Journal of Rural Health*, 19(6), 324-328. <https://doi.org/10.1111/j.1440-1584.2011.01236.x>

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L.S., Lorig, K., & Wagner, E.H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: A Cancer Journal for Clinicians*, 61(1), 50-62.

<https://doi.org/10.3322/caac.20093>

McNulty, J. A., & Nail, L. (2015). Cancer Survivorship in Rural and Urban Adults: A Descriptive and Mixed Methods Study. *Journal of Rural Health*, 31(3), 282–261. <https://doi-org.cyber.usask.ca/10.1111/jrh.12106>

Mbemba, G., Gagnon, M-P., Pare, G., & Cote, J. (2013). Interventions for supporting nurse retention in rural and remote areas: An umbrella review. *Human Resources for Health*, 11(44), 1-9. <https://doi.org/10.1186/1478-4491-11-44>

Moorhead, S., Hazlett, D., Harrison, L., Carroll, J., Irwin, A., & Hoving, C. (2013). A new

- dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of Medical Internet Research*, 15(4), E85. <https://doi.org/10.2196/jmir.1933>
- Nguyen-Pham, S., Leung, J., & McLaughlin, D. (2014). Disparities in breast cancer stage at diagnosis in urban and rural adult women: A systematic review and meta-analysis. *Annals of Epidemiology*, 24(3), 228-235.  
<https://doi.org/10.1016/j.annepidem.2013.12.002>
- Otfinowski, P., Christian, S., Mackenzie, W., Handman, M., & Bultz, B. (2003). Psychosocial oncology care, beyond the tertiary cancer centre. *Canadian Journal of Rural Medicine*, 8(2), 107-111.  
<http://cyber.usask.ca/login?url=https://www.proquest.com/scholarly-journals/psychosocial-oncology-care-beyond-tertiary-cancer/docview/217566528/se-2?accountid=14739>
- Olson, R.A., Lengoc, S., Tyldesley, S., French, J., McGahan, C., & Soo, J. (2012). Relationships between family physicians' referral for palliative radiotherapy, knowledge of indications for radiotherapy, and prior training: A survey of rural and urban family physicians. *Radiation Oncology*, 7, 73. <https://doi.org/10.1186/1748-717X-7-73>
- Olson, R., Nichol, A., Caron, N., Olivotto, I., Speers, C., Chia, S., & ... Tyldesley, S. (2012). Effect of community population size on breast cancer screening, stage distribution, treatment use and outcomes. *Canadian Journal of Public Health*, 103(1), 46-52.  
<https://doi-org.cyber.usask.ca/10.1007/BF03404068>
- Pampalon, R., Hamel, D., & Gamache, P. (2010). Health inequalities in urban and rural Canada:

- Comparing inequalities in survival according to an individual and area-based deprivation index. *Health & Place*, 16(2), 416-420. <https://doi.org/10.1016/j.healthplace.2009.11.012>
- Pesut, B., Hooper, B., Jacobsen, M., Nielsen, B., Falk, M., & O'Connor, B. (2017). Nurse-led navigation to provide early palliative care in rural areas: A pilot study. *BMC Palliative Care*, 16(1), 37. <https://doi.org/10.1186/s12904-017-0211-2>
- Pesut, B., Robinson, C., Bottorff, J., Fyles, G., & Broughton, S. (2010). On the road again: Patient perspectives on commuting for palliative care. *Palliative and Supportive Care*, 8(2), 187-195. <https://doi.org/10.1017/S1478951509990940>
- Peters, P.A. (2019). Broadening the narrative on rural health: From disadvantage to resilience. *University of Toronto Medical Journal*, 96(2), 41-43.
- Polit, D., Beck, C., & Stannard, D. (2012). Essentials of nursing research: Appraising evidence for nursing practice. *Association of Operating Room Nurses. AORN Journal*, 95(2), 307-308. <https://doi.org/10.1016/j.aorn.2011.10.009>
- Prasad, B. (2013). Social media, health care, and social networking. *Gastrointestinal Endoscopy*, 77(3), 492-495. <https://doi.org/10.1016/j.gie.2012.10.026>
- Purtzer, M. A., & Hermansen-Kobulnicky, C. (2012). "Being a part of treatment": The meaning of self-monitoring for rural cancer patients. *Cancer Nursing*, 36(2), 93-103. <https://doi.org/10.1097/NCC.0b013e318263f385>
- Racey, C., & Gesink, D. (2016). Barriers and facilitators to cervical cancer screening among women in rural Ontario, Canada: The role of self-collected HPV testing. *Journal of Rural Health*, 32(2), 136-145. <https://doi-org.cyber.usask.ca/10.1111/jrh.12136>

- Reid-Arndt, S., & Cox, C. R. (2010). Does rurality affect quality of life following treatment for breast cancer? *Journal of Rural Health*, 26(4), 402-405. <https://doi.org/10.1111/j.1748-0361.2010.00295.x>
- Rickards, L. (2011). Rural health: Problems, prevention, and positive outcomes. *Health*, 2011, 149-173.
- Ristevski, E., Regan, M., Birks, D., Steers, N., & Byrne, A. (2015). A qualitative study of rural women's views for the treatment of early breast cancer. *Health Expectations*, 18, 2928–2940. <https://doi.org/10.1111/hex.12277>
- Rodriguez, D.V. (2020). *Cervical cancer screening participation and health literacy in a rural community setting*. (Publication no. 27838355). [Masters thesis, University of Alberta]. Proquest Dissertations Publishing.
- Rogers-Clark, C. (2002). Living with breast cancer: The influence of rurality on women's suffering and resilience. A postmodern feminist inquiry. *Australian Journal of Advanced Nursing*, 20(2), 34–39.  
<https://search.informit.org/doi/10.3316/informit.405460122382587>
- Salehi, A., Frommolt, V., & Coyne, E. (2019). Factors affecting provision of care services for patients with cancer living in the rural area: an integrative review. *Australian Journal of Cancer Nursing*, 20(1), 3–13. <https://doi-org.cyber.usask.ca/10.33235/ajcn.20.1.3-13>
- Saskatchewan Bureau of Statistics. (2021). Economic Review 2019.  
<https://www.saskatchewan.ca/government/government-data/bureau-of-statistics/economic-reports-and-statistics>
- Skalla, K., Bakitas, M., Furstenberg, C., Ahles, T., & Henderson, J. (2004). Patients' need for

- information about cancer therapy. *Oncology Nursing Forum*, 31(2), 313-319.  
[https://doi.org/ 10.1188/04.ONF.313-319](https://doi.org/10.1188/04.ONF.313-319)
- Sibley, L.M., & Weiner, J.P. (2011). An evaluation of access to health care services along the rural-urban continuum in Canada. *BMC Health Services Research*, 11, 20.  
<https://doi.org/10.1186/1472-6963-11-20>
- Statistics Canada. (2011). Population urban and rural, by province (Saskatchewan).  
<https://www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/demo62i-eng.htm>
- Stephen, J., Rojubally, A., Macgregor, K., Mcleod, D., Speca, M., Taylor-Brown, J., ... Mackenzie. (2013). Evaluation of CancerChatCanada: A program of online support for Canadians affected by cancer. *Current Oncology (Toronto, Ont.)*, 20(1), 39-47.  
[https://doi.org/ 10.3747/co.20.1210](https://doi.org/10.3747/co.20.1210)
- Swanson, J., & Koch, L. (2010). The role of the oncology nurse navigator in distress management of adult inpatients with cancer: A retrospective study. *Oncology Nursing Forum*, 37(1), 69-76. <https://doi.org/10.1188/10.ONF.69-76>
- Tariman, J., Doorenbos, A., Schepp, K., Singhal, S., & Berry, D. (2014). Information needs priorities in patients diagnosed with cancer: A systematic review. *Journal of the Advanced Practitioner in Oncology*, 2014(5), 115-122. <https://www-ncbi-nlm-nih.gov.cyber.usask.ca/pmc/articles/PMC4042668/>
- Thorne, S. (2016). *Interpretive description (Developing qualitative inquiry)* 2<sup>nd</sup> ed. New York, NY: Routledge.
- Thorne, S., Kirkham, S., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in*

*Nursing, & Health*, 20(2), 169-177. [https://doi.org/10.1002/\(SICI\)1098-240X\(199704\)20:2<169::AID-NUR9>3.0.CO;2-I](https://doi.org/10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I)

Thorne, S., Kirkham, S., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1-11.

<https://doi.org/10.1177/160940690400300101>

Tyldesley, S. & Mcgahan, C. (2010). Utilization of radiotherapy in rural and urban areas in British Columbia compared with evidence-based estimates of radiotherapy needs for patients with breast, prostate and lung cancer. *Clinical Oncology*, 22(7), 526-532.

Weaver, K., Geiger, A., Lu, L., & Case, L. (2013). Rural - urban disparities in health status among US cancer survivors. *Cancer*, 119(5), 1050-1057. <https://doi.org/cyber.usask.ca/10.1007/s10552-013-0225-x>

Weaver, B., Lindsay, B. & Gitelman, B. (2012). Communication technology and social media: Opportunities and implications for healthcare systems. *Online Journal of Issues in Nursing*, 17(3), 3. <https://10.3912/OJIN.Vol17No03Man03>

Wilkes, L., & White, K. (2005). The family and nurse in partnership: providing day-to-day care for rural cancer patients. *Australian Journal of Rural Health*, 13(2), 121-126.

<https://doi.org/>

10.1111/j.1440-1854.2005.00666.x

Wilkes, L.M., White, K., Mohan, S., , & Beale, B. (2006). Accessing metropolitan cancer care services: Practical needs of rural families. *Journal of Psychosocial Oncology*, 24(2), 85–101. <https://doi.org/10.1300/J077v24n02-06>

Wilson, D. M., Fillion, L., Thomas, R., Justice, C., Bhardwaj, P. P., & Veillette, A. (2009). The

"good" rural death: A report of an ethnographic study in Alberta, Canada. *Journal of Palliative Care*, 25(1), 21-9.

<http://cyber.usask.ca/login?url=https://www.proquest.com/scholarly-journals/good-rural-death-report-ethnographic-study/docview/214198527/se-2?accountid=14739>

Yackzan, S., Stanifer, S., Barker, S., Blair, B., Glass, A., Weyl, H., & Wheeler, P. (2019).

Outcome measurement: Patient satisfaction scores and contact with oncology nurse navigators. *Clinical Journal of Oncology Nursing*, 23(1), 76-81. <https://doi.org/10.1188/19.cjon.76-81>



Appendix A: Recruitment Poster

**Department of Nursing  
University of Saskatchewan**



**PARTICIPANTS NEEDED FOR  
RESEARCH IN RURAL CANCER CARE**

We are looking for volunteers to take part in a study of rural women's experiences on cancer care. Volunteers must be living in an area with a population of less than 10 000 people and live at least 100 km from Regina

If you have ever been enrolled in, or are currently enrolled in, a clinical research trial at the Allan Blair Cancer Centre you cannot participate in this study.

As a participant in this study, you would be asked to: participate in a face to face interview and a follow up interview by telephone.

The interviews would be less than 60 minutes long.

For more information about this study, or to volunteer for this study, please contact:

*Sarah Taylor, Masters of Nursing Student*  
at 306-337-3811 or

Email: [sarahj.taylor@usask.ca](mailto:sarahj.taylor@usask.ca)

Or

*Dr. Pammla Petrucka, Professor, University of Saskatchewan*  
at 306-337-3811 or

Email: [pammla.petrucka@usask.ca](mailto:pammla.petrucka@usask.ca)

**This study has been reviewed by, and received approval through, the Behavioural Research Ethics Office, University of Saskatchewan and the Saskatchewan Cancer Agency**

## Appendix B: Consent Form

# **Consent Form: Rural People's Perspectives on Cancer Care in South Eastern Saskatchewan**

Please read this form carefully, and feel free to ask questions you might have.

### **Principal Investigators:**

#### **Sarah Taylor, RN, BSN, Master's Student**

College of Nursing, University of Saskatchewan, Regina Campus, Regina SK

Phone: 306-337-3811 Email: sarahj.taylor@usask.ca

#### **Pammla Petrucka, RN, PhD, Thesis Supervisor, Professor**

College of Nursing, University of Saskatchewan, Regina Campus, Regina SK

Phone: 306- 337-3811 Email: [pammla.petrucka@usask.ca](mailto:pammla.petrucka@usask.ca)

**Purpose and Procedure:** Women with a cancer diagnosis living in rural areas often face unique burdens in screening, prevention, diagnosis and treatment. We would like to improve understanding of the issues rural patients such as yourself, face.

To participate in this study, you need to be:

- At least 18 years of age
- A woman diagnosed with cancer who has received treatment in the last 5 years
- Currently living in an area in Saskatchewan that has a population less than 10 000 people
- Outside the commuting zone of Regina (more than 100 km)

Participation in the study involves:

- One interview, less than an hour long
- A follow up interview by phone, less than an hour long

The interview will be at a location and time that is convenient to you.

**Potential Benefits:** Your participation will help us understand the experiences of people diagnosed with cancer and living in a rural area in Saskatchewan. You personally may not benefit from this, but your contribution may lead to positive improvements in rural cancer care for health care providers and could help direct further research. Your participation may positively impact rural health policies.

**Potential Risks:** Some may be uncomfortable when speaking about their rural health experiences. Resources to support your mental health will be provided if requested. Your choice to participate or not will not affect the health care services you receive in any way and your health care providers will never know whether or not you participated in this study.

**Confidentiality:** The information that you share will not be shared with anyone except my supervisor and thesis committee. When this research is published, no identifying characteristics or specific details will be included in any of the findings to be certain that no one can identify what you have said.

**Storage of Data:** The interviews will be audiotaped and transcribed into written form. All of the information you share for the research will be kept separate from your name and other identifying information. Information stored on the researcher's computer will be securely password protected. The consent form and all other data will remain in a locked cabinet for five years at which time the data will be destroyed.

**Right to Withdraw:** You may withdraw from this study at any time, for any reason, with no consequence. Your information can be removed and destroyed at any time until the data analysis has been completed, at which time it is not possible to remove your contribution.

**Questions:** If you have any questions concerning the research project, please feel free to ask at any point by contacting the researchers at the numbers or emails provided at the top of the page. If you have any questions about your rights as a participant, you can call the University of

Saskatchewan's Ethics Office toll free at 1-888-966-2975 or [ethics.office@usask.ca](mailto:ethics.office@usask.ca)

**Consent to Participate:**

I have read and understood the description provided. I have had any questions I had about this study answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time. A copy of this consent form has been given to me for my records.

\_\_\_\_\_ (Name of Participant)

\_\_\_\_\_ (Date)

I would like the opportunity to review the transcript from my interview before any of my quotes are used in this study: Yes No

**If you would like to go over the transcripts from your interview, to add to or change anything that you said, please circle yes and a time for that will be arranged with you.**

I would like to receive a summary of the results of the study when it is complete: Yes No

Please send it to my mailing address: \_\_\_\_\_

OR to my email address: \_\_\_\_\_

## Appendix C: Interview Guide

### Interview Guide

1. How far from Regina is your residence?
2. Do you consider yourself to live in a rural area?
3. Can you tell me about your diagnosis?
4. Where is the first place you go to receive healthcare? Have you had to travel for treatment?
5. Tell me about your past experiences for accessing treatment or medical expertise related to your current care?
6. How are you being supported with symptoms from your cancer and side effects from your cancer treatment?
7. What is your experience around informal support systems for cancer care in your rural area?
8. Tell me about balance in your life since receiving your cancer diagnosis (i.e., work, family time, spirituality, mental wellbeing)
9. Tell me about your experience since receiving your cancer diagnosis. (prompt: satisfied? Anything else about your experience you want to share?)
10. Have you found any gaps in cancer services or support programs that I have not asked about?
11. Is there anything else you would like to tell me?