

Running Head: SUPPORTIVE CARE

**Supportive Care Experiences of Rural Women Living with Breast Cancer: An
Interpretative Descriptive Qualitative Study**

By

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Abstract

Breast cancer is the leading cause of female cancer in Manitoba. The purpose of this qualitative study was to arrive at an increased understanding of the supportive care experiences of rural women requiring treatment for invasive breast cancer. Twenty women from four regional health authorities participated in the study. Data was collected using face-to-face, semi-structured interviews and analyzed by content analysis through an interpretative qualitative lens. The findings have provided a holistic overview of the supportive care experiences of women living with breast cancer that are uniquely Manitoban and captured both the positive aspects of living rurally and the challenges that present in the face of a cancer diagnosis. The findings are supported by the literature and will be of keen interest to health providers from this province. Pragmatic recommendations have been generated from the study findings with implications to inform practice, education and research.

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Dedication

I dedicate this work to the twenty remarkable women who participated in this study and openly shared the personal and intimate details of their cancer experience. I would not have been able to realize this important research without their thoughtful contribution to this work. It will be an honor and privilege to share your journey with the cancer community with the hopes to improve services for all people living with cancer who live in rural settings.

Table of Contents

Abstract.....	i
Acknowledgements.....	ii
Dedication.....	iii
Table of Contents.....	iv
List of Tables.....	ix
 Chapter One: Statement of Problem	
Introduction.....	1
Purpose and Research Objectives.....	4
Definitions of Major Constructs.....	4
Assumptions and Preliminary Work.....	5
Significance of Study.....	8
Chapter Summary.....	8
 Chapter Two: Conceptual Framework	
Introduction.....	9
Supportive Care Framework.....	9
Chapter Summary.....	11
 Chapter Three: Literature Review	
Introduction.....	12
Breast Cancer Overview.....	12
Supportive Care Needs of Women Living with Breast Cancer.....	20
Supportive Care.....	37
Supportive Care Services in Manitoba for Women Living with Breast Cancer.....	43
Chapter Summary.....	47

Chapter Four: Methodology

Introduction.....	49
Discussion of Chosen Methodology.....	49
Research Methods and Procedures.....	53
Methodological Rigour and Trustworthiness.....	60
Ethical Considerations.....	63
Chapter Summary.....	70

Chapter Five: Demographic Findings

Introduction.....	71
Participant Sample.....	71
Treatment Modality and Breast Cancer Demographics.....	73
Regional and Travel Demographics.....	75
Chapter Summary.....	77

Chapter Six: Supportive Care Findings

Introduction.....	78
Physical Domain.....	78
Symptom of Illness and Diagnosis.....	79
Side Effects of Treatment.....	81
Psychomotor Care Processes.....	91
Managing Emergencies.....	93
Domain Summary.....	94
Informational Domain.....	96
Health Care Providers.....	96
Informational Resources.....	106

Supportive Programs and Services.....	108
Domain Summary.....	110
Social Domain.....	111
Social Networks.....	111
Rural Life.....	114
Communication with Others.....	116
Social Isolation.....	119
Domain Summary.....	121
Practical Domain.....	123
Activities of Daily Living.....	123
Instrumental Activities of Daily Living.....	124
Provision for Family.....	126
Travel.....	128
Accommodations.....	133
Employment.....	134
Financial Implications.....	135
Domain Summary.....	138
Emotional Domain.....	140
Emotional Response to Illness.....	140
Releasing Emotions.....	148
Emotional Support.....	149
Families Response to Illness.....	152
Domain Summary.....	154
Psychological Domain.....	155

Unmet Psychological Needs.....	155
Gaining Personal Control and Wellbeing.....	160
Personal Attributes.....	164
Domain Summary.....	168
Spiritual Domain.....	169
Facing Mortality.....	169
Spiritual Practices and Beliefs.....	172
Search for Meaning.....	173
Gaining New Perspective.....	175
Domain Summary.....	179
Chapter Summary.....	179
Chapter Seven: Discussion of Findings	
Introduction.....	181
Discussion of the Supportive Care Domains.....	181
Physical Domain.....	181
Informational Domain.....	187
Social Domain.....	191
Practical Domain.....	194
Emotional Domain.....	200
Psychological Domain.....	208
Spiritual Domain.....	214
Discussion Summary.....	217
Study Limitations and Strengths.....	218
Chapter Summary.....	219

Chapter Eight: Recommendations and Conclusions

Introduction.....220

Recommendations.....220

 Recommendations for Practice.....220

 Recommendations for Education.....226

 Recommendations for Research.....227

Chapter Summary.....227

References.....228

List of Appendices.....252

Appendices.....253

List of Tables**Chapter Five**

Table 1: Breast Cancer Participants and Sample Description.....	71
Table 2: Treatment Modality Demographics.....	74
Table 3: Regional and Travel Demographics.....	75

Chapter Six

Table 1: Physical Domain Summary.....	77
Table 2: Informational Domain Summary.....	95
Table 3: Social Domain Summary.....	110
Table 4: Practical Domain Summary.....	122
Table 5: Emotional Domain Summary.....	139
Table 6: Psychological Domain Summary.....	154
Table 7: Spiritual Domain Summary.....	168

Chapter One: Statement of the Problem

Cancer is a devastating disease that affects every aspect of a person's life. The burden of cancer on the Canadian population is staggering. Everyday 500 Canadians are diagnosed with cancer and 200 individuals will succumb to the illness (Canadian Cancer Society [CCS], 2012). In 2017, an estimated 206,200 Canadians were diagnosed with cancer and 80,800 cancer deaths occurred. As well, cancer prevalence and survival are on the rise (CCS, 2017). As of January 2009, 810,045 Canadians received a cancer diagnosis within the previous 10 years and remain alive on that date. This illustrates that approximately 2.4% of Canadian people were living with a diagnosis of malignancy and illness related challenges in the decade leading up to 2009 (CCS, 2017). Prevalence and survival data is statistically significant and a growing interest in public health. The challenges of illness, toxicity of treatment, complex iatrogenic effects and rise in secondary malignancies will have a significant impact on the population and Canadian health care systems (Schulmeister, 2007). Age remains a major risk factor for the development of cancer (Langhorne, Fulton, & Otto, 2007). Consequently, the number of incident cases of cancer will continue to rise in the coming years as the baby boomers grow old and as a result the burden of illness will continue to escalate.

All people living with cancer are faced with many demanding challenges, including effects on quality of life and well-being, uncertainty about treatment options, treatment-related toxicity, and concerns about long-term outcomes. Uncertainty, hopelessness, dependence, role changes, and an ongoing search for meaning throughout the illness are also common experiences (Fitch, 2009; Shaha, Cox, Talman, & Kelly, 2008). All cancer patients require supportive care during the illness trajectory from a holistic perspective. Individuals have many human needs related to physical, practical, social, informational, emotional, psychological, and spiritual

entities (Fitch, 2009). Throughout the cancer journey, a person's capacity to meet these needs may be compromised (Fitch, 2009). Supportive care in cancer is a philosophical approach to service provision based on human needs. Through interdisciplinary collaboration, supportive care seeks to improve and preserve quality of life, autonomy, and dignity of those living with cancer (Fitch, Porter & Page, 2009). Supportive care is a service delivery model adopted by CancerCare Manitoba [CCMB] and is integral to the practice of all health care providers (HCP) working with individuals living with cancer (CCMB, 2009).

In Manitoba in 2016, 3,300 men and 3,400 women were diagnosed with cancer (CCS, 2017). The leading cause of cancer related illness in a man is prostate cancer and in a woman is breast cancer. Lung and colorectal cancer follow, as the second and third major cause of cancer. These top four malignancies represent over half the cancer diagnoses and remain the biggest burden on our health care system (CCS, 2017). It is expected that in Manitoba, by the year 2025, cancer incidence will increase by 45-54% and cancer prevalence will increase by 75-84%. There will be approximately 58,000 to 61,000 individuals living with cancer in this province, which represents approximately 5% of the Manitoban population (Kliewer, Wajda, & Blanchard, 2001). Considering this substantial increase in the number of incident and prevalent cancer cases over the next decade, service provision challenges, access to oncology expertise and supportive care services remains an ongoing and mounting concern (Kliewer et al., 2001).

Approximately one third of the Manitoba population lives outside of Winnipeg with a steady growth demonstrated in the rural population in the last five years (Bollman & Clemenson, 2008; Government of Manitoba, 2011). To further complicate the scope of this problem, 40% of the cancer population live in rural or remote areas of Manitoba (Kliewer et al., 2001).

CancerCare Manitoba, located in Winnipeg, is the center of excellence for oncology care in the

province. While, major initiatives are underway to improve the cancer journey and access to service for all Manitobans living with cancer, there continues to be evidence that there are variations in cancer survival and fragmentation of services that affect rural individuals when faced with this diagnosis (CCMB, 2009; Government of Manitoba, 2012). Considering the complexity of cancer service and treatment, it is paramount to develop a broad understanding of the gaps in service and challenges facing individuals living with cancer who reside in rural areas.

Cancer is a complex illness and over 200 different cancer-related diagnoses exist (Langhorne et al., 2006). Each disease site has individualized complex treatment regimens and unique treatment-related problems (Langhorne et al., 2006). Based on the enormous scope and complexity of cancer, the focus of this research project is on women living with breast cancer who reside in rural areas of Manitoba.

Invasive, ductal carcinoma accounts for approximately 80% of all incidence cases of breast cancer (Crane-Okada & Loney, 2007). A diagnosis of this magnitude signals a number of difficult challenges featuring multi-modality treatment plans that involve a combination of surgery, chemotherapy, radiation, biologic therapy, and long term hormone treatment (Crane-Okada & Loney, 2007). The scope of the problem accelerates for rural women living with breast cancer related to lack of access to oncology care and fragmentation of services available in rural settings. Subsequently, many additional unmet supportive care needs exist that are unique to this population. The literature abounds with studies related to the supportive care needs of women living with breast cancer. However, research that situates experiences specific to the rural living is limited. After an extensive search of the literature, only two older studies were revealed in Canadian literature featuring the unmet needs of rural women living with this illness (Gray, James, Manthorne, Gould, & Fitch, 2004; Fitch et al., 2003). In order to ensure that the needs of

rural women living with breast cancer in Manitoba are met, research that situates their experiences at the center of inquiry is warranted. To explore this phenomenon, an interpretive descriptive qualitative study was completed and sample, treatment and travel demographics, findings, discussion, and recommendations will be presented in the upcoming chapters.

Purpose and Research Objectives

The primary purpose of this qualitative study was to arrive at an increased understanding of the supportive care experiences of adult women requiring treatment for invasive breast cancer (IBC) and who reside in rural Manitoba. The objectives guiding this study are:

1. To describe the supportive care experiences of women living with IBC who require multi-modality treatment regimens and reside in rural Manitoba.
2. To explore how the supportive care experiences change from detection to the end of the treatment phase of illness specific to living in a rural setting.
3. To identify recommendations on how to improve the supportive care experiences of rural women living with breast cancer in the province.

Definitions of Major Constructs

For the purpose of the study four major constructs were identified and defined. These constructs are: invasive breast cancer, supportive care, rural, and understanding.

Invasive breast cancer. Breast cancers are classified according to cell type and infiltrating capacity. Once the malignancy infiltrates outside the ducts or lobules and into the surrounding tissue it is described as invasive (Crane-Okada & Loney, 2007).

Supportive care. Supportive care encompasses human needs, cognitive appraisal, coping, and adaptation (Fitch, 2009). Considering the cancer experience supportive care is defined as “the provision of the necessary services as defined by those living with or affected by

cancer to meet their physical, social, emotional, informational, psychological, spiritual, and practical needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases of cancer care, encompassing issues of survivorship, palliation, and bereavement” (Fitch, 1994; Fitch, 2000, pp. 41).

Rural. The role of place in shaping a person’s cancer experience is the basic foundation of inquiry in this study. A rural area resident includes all persons living outside the census metropolitan area (CMA) of Winnipeg. The CMA of Winnipeg includes the City of Winnipeg and the municipalities of West St. Paul, East St. Paul, Headingly, MacDonald, Richot, Tache, Springfield, Rosser, St. Francois Xavier, St. Clements, and Brokenhead First Nations (City of Winnipeg, 2014).

Understanding. Developing a deeper understanding of a clinical phenomenon allows the researcher to capture patterns that will become immersed in the data based on subjective perceptions. By exploring meanings and explanations it provides the researcher with insight to inform clinical understanding (Thorne, Kirkham & O’Flynn-Magee, 2004).

Assumptions and Preliminary Work

My twenty year oncology nursing career has provided me with a deeper understanding of the challenges that face cancer patients from rural and remote areas of the province. Working in both in and out-patient settings, with multiple disease sites and a variety of complex treatment regimens, I have witnessed these challenges from a broader lens. Cancer treatments and related complications escalate based on the stage and grade of the malignancy. Treatment for limited stage disease is very different than aggressive, advanced stages of illnesses. Each treatment phase has its associative challenges and when relocation for treatment is required it escalates the demands and stress placed on the individual and family.

In my career I have cared for hundreds of cancer patients from rural areas of the province and witnessed many disturbing findings. Declaration of personal bankruptcy, loss of family home, lengthy separations from families or friends, employment challenges, refusing treatment because of the inability to relocate, divorce and family difficulties, or having to make treatment decisions based on geographic location are some of the examples that come to mind. While similar challenges can occur with people living in urban settings, problems such as this escalate for our rural dwellers. These disparities compound the experiences of this life-altering illness.

During my preliminary work in graduate studies I had the opportunity to explore supportive care services available to individuals living in rural or remote communities based on a critical review of the literature and practicum experience. The literature suggests rural cancer patients face distinctive social disruptions and service provision challenges compared to their urban counterparts (Gray et al., 2004; Rogers-Clark, 2002). Other notable findings include delays in diagnosis, travel burden challenges, access to services, economic disparities (Fitch et al., 2003; Gray et al., 2004; Martin-McDonald, Rogers-Clark, Hegney, McCarthy, & Pearce, 2003; McGrath, 2001; Wilkes, White, Mohan, & Beale 2006) and treatment decisions based on geographic location (Celaya, Rees, Gibson, Riddle, & Greenberg, 2006; Punglia, Weeks, Neville, & Earle 2006). One of the limitations of my review was the lack of scholarly literature of this chosen topic in the Canadian population. Living in Canada comes with distinctive challenges such as long winters, poor driving conditions, or travelling lengthy distances. Since many of the studies reviewed were international-based it is also difficult to ascertain what service provision and supportive care services exist in different settings. Based on these limitations, further research is warranted for Canadians living with cancer in rural areas.

During my practicum experience I was able to have many informal discussions with key informants from the Community Cancer Program (CCP), Uniting Primary Care and Oncology (UPCON), Women's Cancer Center of Hope (WCCH), Rural Navigation Program, in and out patient oncology settings, and Manitoba (MB) Telehealth. I also had the opportunity to spend two days in rural CCP sites. Collectively, through my discussion with these key practitioners, I was able to gather details of the services that were available in rural settings and those that are not. It became overwhelmingly clear that different challenges exist for each disease site and the scope of the problem is staggering. Fragmentation of service for the rural oncology population exists despite emerging rural initiatives such as the CCP and navigation programs. It became evident that Winnipeg will remain the center of excellence for oncology care in our province and extension of oncology expertise into rural settings is limited.

Breast cancer became the focus of my interest for a number of reasons. First, after a lengthy discussion with Lori Santoro, Nurse Clinician and Navigator, WCCH, some breast sub-optimal cancer surgeries still occur in rural settings requiring additional consultation with a more experienced surgeon. Although, I did not witness this in this study it continues to remain a concern with our breast cancer disease-site HCP. The staff at WCCH has implemented strategies to increase awareness advocating that all breast cancer surgeries in the province be performed where appropriate expertise is positioned (Lori Santoro, Personal Communication, January 30, 2014). Second, while exploring the CCP in Manitoba, it was revealed that breast cancer adjuvant chemotherapy and biologic therapies can be delivered rurally. It is crucial to explore the potential benefits of existing services that are located in rural settings. Additionally, the positive aspect of rural living including having treatment closer to home was frequently noted in the literature and needs to be considered as part of the research project. Third, a major component of breast cancer

adjuvant therapy includes radiation therapy. Most women receiving radiation therapy are required to relocate to an urban setting. Therefore, it is imperative to capture the impact that relocation has on patients and families. Finally, breast cancer is the leading cause of illness in the Manitoba female population making it an important health topic that requires the attention of researchers, policy makers and major cancer stakeholders.

Significance of the Study

The Canadian research on the rural cancer experience is limited. With rising incidence and prevalence in breast cancer in our country, it remains an important health topic. Moreover, a significant population of Manitoba people live in rural areas of the province with limited access to supports and services. The findings from this study have provided a holistic overview of the supportive care experiences of women living with breast cancer that are uniquely Manitoban and captured both the positive aspects of living rurally and the challenges that present in the face of a cancer diagnosis. The findings are strongly supported by the literature and will be of keen interest to HCP. Pragmatic recommendations have been generated from the study findings with implications for practice, education and research and may be used to inform practice.

Chapter Summary

Chapter one provided an overview of the background, rationale, assumptions, and significance of the current research regarding the needs and supportive care experiences of women requiring treatment for IBC and who reside in rural Manitoba. In chapter two, the supportive care framework will be detailed. This framework was used to guide the review of the literature and a model underpinning this research initiative.

Chapter Two: Conceptual Framework

Chapter two describes the Supportive Care Framework and how it was used in this study. A conceptual framework is not traditionally applied to qualitative studies and often researchers espouse the value of an atheoretical stance to their research (Struebert & Carpenter, 2011). However, an interpretive description is a coherent conceptual narrative that describes patterns and commonalities in the phenomenon under review. A theoretical framework can be useful to guide the research process (Thorne et al., 2004). The framework was useful in the development of the interview process and helped to inform data analysis. Additionally, the framework was used to categorize the findings according to the seven domains and guide the discussion and recommendation. Following will be an overview of the Supportive Care Framework.

Supportive Care Framework

The Supportive Care Framework was initially proposed in 1994 (Fitch, 1994). The driving force behind the development of the framework was to provide a tool for HCP to conceptualize what type of assistance cancer patients might need and how planning for service delivery might be approached (Fitch, 2000; Fitch, 2009). A task force group consisting of patients, families, and various health disciplines gathered to provide expert opinions on the needs of cancer patients. Collectively, by sharing experiences and a broad range literature review on adaptation and coping, the framework was developed (Fitch, 2009).

The underlying philosophical ideology and constructs that are inherent in the framework include human needs, cognitive appraisal, coping, and adaptation (Fitch, 2000; Fitch, 2009). Human needs encompass physical, emotional, psychological, social, and spiritual entities. Individuals develop a collection of daily skills to meet their own needs. As life events unfold, effective ways to meet these needs may vary and can create challenges. When difficult life

demands occur and basic needs are not met it can lead to uncertainty or loss of control. Cognitive appraisal or human response to a specific situation is uniquely dependent on each individual. Appraisal of a life-altering event can result in emotional responses based on a perceived threat. When the threat is beyond the person's control, emotional distress will escalate. Coping skills are developed across a life time and will vary from person to person. When a perceived threat or emotionally distressing situation arises the complexity of coping behaviors can challenge individuals. For adaptation to occur the coping behaviors must be effective to meet the individual needs in any given situation (Fitch, 2000; Fitch, 2009).

Cancer is an unanticipated life event. A cancer diagnosis can create new demands, anxiety, feelings of vulnerability, and uncertainty when basic human needs are not met and challenge individuals at times of distress (Fitch, 2009). When individuals enter the cancer system, the pathway of experiences can be confusing and chaotic and will inevitably vary from person to person depending on the individual malignancy and treatment plan. Individuals have a wide range of needs that are more than just physical in nature. Additional needs occur which include social, psychological, emotional, spiritual, informational, and practical needs which impact the overall experience. These needs will invariably escalate as treatment complexity increases and many individuals will require specialized professional intervention that can be intensive, lengthy, and complex. In addition, navigating the system throughout the journey adds additional burdens for patients and families (Canadian Association of Nurses in Oncology [CANO], 2001; Fitch, 2000; Fitch, 2009). An outline of this domain-specific need framework is featured in Appendix C. Operational definitions are provided and examples illustrated. Further description of the supportive care needs for women living with breast cancer will be outlined in the Chapter three.

The Supportive Care Framework is implemented under the CCMB umbrella (CCMB, 2009) as an appropriate model for service delivery and widely used by both national and international agencies (Aranda, 2009; Fitch 2009.) The concepts inherent within the framework have been validated in qualitative research initiatives (Gray et al., 2004; Shaha et al., 2008) and tested for reliability and validity in the form of a supportive care needs survey in quantitative works (Boneveski et al., 2000; White et al., 2011). The concepts appear regularly in the scholarly and empiric literature underpinning research, curriculum development, nurse-led supportive care clinics, policy, and program development (Fitch et al., 2009).

Chapter Summary

The Supportive Care Framework (Fitch, 1994) has made a significant contribution to cancer service delivery by illustrating a holistic patient and family-centered approach to the care across throughout the treatment trajectory. Individuals will respond to a cancer diagnosis or its treatment in their own distinctive way and tailored interventions based on this multi-domain framework will assist with meeting basic human needs and assist with coping and adaptation to the illness experience (Fitch et al., 2009). Through this study, many supportive care needs facing rural women were exposed from the interviews. The findings were categorized according to the seven domains in the framework and guide the discussion and recommendation sections to follow. Tailored recommendations were developed and detailed in Chapter 8. The following chapter provides a summary of breast cancer through each phase of illness, supportive care needs of women living with breast cancer and supportive care services available for rural individuals living with cancer in the national, international and Manitoba population. The Supportive Care Framework was utilized to guide the literature review featured in the following chapter.

Chapter Three: Literature Review

A review of the breast cancer literature is presented in this chapter which provides a foundation to explore the phenomenon of supportive care needs and experiences of rural women living with breast cancer. An overview of breast cancer is provided which includes epidemiology, etiology and risk factors, screening and detection, diagnosis and staging, treatment, and follow-up phases of illness while featuring cancer services in Manitoba. Next, the supportive care needs of women living with breast cancer according to the domains in the supportive care framework will be detailed. In addition, some specific rural challenges will also be highlighted. Subsequently, an overview of supportive care service available to persons' living with cancer in rural areas based on the national and international literature will be featured. Finally, supportive care services for women living with breast cancer in Manitoba will be detailed.

Breast Cancer

Epidemiology

Breast cancer is an important public health topic and the leading cause of cancer in the female population. It is estimated that one in nine Canadian females will develop breast cancer in their lifetime (CCS, 2013a). A dramatic increase in breast cancer incidence rates occurred in the early to mid 1990's. Subsequently, incidence and mortality rates fluctuated with a downward trend accelerating by 2.4% per year since 2000. This is assumed to be linked to increased awareness of lifestyle risk factors, ongoing implementation of breast screening initiatives, and more effective therapies following surgical interventions (CCS, 2013a, CCS, 2017). In Manitoba, in 2017, 860 women were diagnosed with breast cancer (CCS, 2017). Breast cancer incidence rates are consistent across the province but it remains that the highest incident rates

occur in North Eastman and Interlake regions of the province (CCMB, 2010). However, with an aging population, actual and projected breast cancer cases are on the rise. It is projected by the year 2026 there will be over 1000 new cases diagnosed each year in this province (CCMB, 2010). In addition, breast cancer is the second leading cause of cancer-related mortality in our female population. Thirteen percent of Canadian women lost their life to breast cancer in 2017 and in Manitoba there were 160 deaths (CCS, 2017). However, mortality rates are declining based on improved screening and more effective therapies (CCS, 2017). Survival data is directly linked to stage of disease (CCS, 2007; Langhorne et al., 2007). The majority of women diagnosed at Stage I and II have an increase disease free survival whereas, if diagnosed at stages III or IV, prognosis worsens (CCS, 2007).

Etiology and Risk Factors

There is no single cause of breast cancer. Breast cancer is a heterogeneous disease featuring a number of variable factors (Crane-Okada & Loney, 2007). There are many modifiable and non-modifiable risk factors associated with the development of this malignancy that can be categorized as reproductive/hormonal, lifestyle, and heredity. With age and prolonged exposure to estrogen as major risk factors, it remains that post-menopausal women are at a much higher risk for the development of the disease (Crane-Okada & Loney, 2007; CCS, 2007). Other risk factors include obesity, fat consumption, radiation exposure, or alcohol consumption (Crane-Okada & Loney, 2007). Approximately 52% of cases occur between the age of 50-69 years, 30% over the age of 69 years and 18% under the age of 50 years (CCS, 2013a). Although, the supportive care needs may vary based on age, all adult women with a diagnosis of IBC have been included in this study.

Screening and Detection

Early detection remains imperative for breast cancer control and yields a better prognosis. Mammography, professional, and self-breast exam are the mainstay methods of early detection (Crane-Okada & Loney, 2007). Primary prevention, screening, early detection, and reducing wait times are part of the strategic direction of CCMB. The primary goal is to decrease cancer incidence and improve patient outcomes and survival once cancer is detected (CCMB, 2010; Government of Manitoba, 2012). Manitoba Breast Screening Program has been underway for a number of years with the aim to screen the majority of women between the ages of 50 to 69 years with yearly mammography. Mortality rates have been reduced by 24 % in women who were involved in this program (CCMB, 2010). The use of mobile ultrasound in rural Manitoba and introducing digital mammography are initiatives underway by the Government of Manitoba in collaboration with CCMB (CCMB, 2010; Government of MB, 2012). Mobile ultrasound is available every two years in various regions across the province. Women are required to be registered for this program and notified when the diagnostic service is available in their area. Breast Health Center at the St. Boniface Hospital also has an initiative in progress which will provide access to diagnostic and surgical oncology expertise that promotes early detection of this illness (Government of MB, 2012). As part of the Manitoba 'In Sixty' Cancer Patient Journey Initiative, clinical guidance pathways were established and available on the CCMB website to direct primary care providers and promote early detection and diagnosis (CCMB, 2013a; CCMB, n.d. b). While these important programs exist in Manitoba, access to diagnostics support remains an ongoing challenge for rural dwellers. According to CCMB (2010), average wait times for mammography are approximately 25-28 days, while the longest wait times for mammography occur in the northern part of the province which exceeds 40 days.

Diagnosis and Staging

A tissue diagnosis and staging evaluations are the next step in the cancer process. Invasive, ductal carcinoma accounts for approximately 80% of all incidence cases of breast cancer (Crane-Okada & Loney, 2007). According to Lori Santoro, Nurse Clinician, WCCH, a fine-needle aspirate is typically performed by primary care physicians in many rural settings but a core or stereotactic biopsy and other staging evaluations require relocation to an urban setting (Personal communication, January 30, 2014). Churchill, MB refers patients to Winnipeg for all diagnostic services. Thompson, MB, provides mammography and breast ultrasound services but refers to Winnipeg for core biopsies. Boundary Trails Health Centre and Brandon Western Cancer Center provides mammogram, breast ultrasound and core or stereotactic biopsies (CCMB, 2013b). Rural women need to be referred to Winnipeg if they are not living close to a site with these diagnostic services. Once a diagnosis is determined, staging evaluations are required. A series of tests, including blood work, bone scan and chest and abdomen imaging with Computerized Tomography (CT) Scan or Magnetic Resonance Imaging (MRI) are required (National Comprehensive Cancer Network [NCCN], 2014). While CT scanning is available in various sites across the province, access to nuclear medicine tests or MRI is not available in rural settings. Travel will be required for many rural women during this diagnostic period.

Despite improvements related to the implementation of primary and secondary prevention strategies, women in Manitoba continue to be diagnosed with this malignancy in more advanced stages. Approximately 58% of women diagnosed were confirmed Stage II, III or IV at time of diagnosis when treatment plans become much more complicated (CCMB, 2011). The percentage of women diagnosed in advanced stage of illness is approximately 6-7% and is consistent across the province. However, stage IV presentations are the highest in the South East part of the province at 8% and the lowest in the Interlake at 4.3% (CCMB, 2010). Metastatic

disease (Stage IV) was not the focus of this research as the treatments regimens are exclusive to these populations. This research focused on women with Stage II-III IBC.

Treatment

Once breast cancer is detected and diagnostic and staging evaluations are completed, treatment plans are established (Langhorne et al., 2007; NCCN, 2014). At this point in the cancer journey a visit to a surgical and medical oncologist at CCMB is required. Treatment plans are based on a number of factors including the stage and grade of the disease, other co-morbid conditions, and performance status of the individual (Langhorne et al., 2007; NCCN, 2014). The scope of these treatment plans is complex, challenging, and lengthy. Invasive breast cancers require multi-modality treatment regimens including surgery, radiation, systemic, and long term hormone therapy. Some women also require biologic therapies that are determined based on their initial pathology (NCCN, 2014).

Surgery. Lumpectomy or modified radical mastectomy and sentinel node dissection is the first line of therapy for IBC. Radical mastectomy is rarely offered in this circumstance (Crane-Okada & Loney, 2007; NCCN, 2014). For women receiving mastectomies breast reconstruction is an available option at the time of the original surgery but adds a dimension of complexity to the surgical procedure and recovery process. Tissue expanders and skin graft from the abdomen, upper back or the buttock area and breast augmentation is standard procedure (Crane-Okada & Loney, 2007; NCCN, 2014). This extensive surgical intervention is not performed in rural Manitoba and is currently only available in Winnipeg requiring relocation for up to two weeks. Many post cosmetic surgeries may also be required including breast reshaping, nipple tattooing, and repair of skin flaps or scarring (Crane-Okada & Loney, 2007; NCCN, 2014). This further extends the treatment journey for many women who chose these cosmetic options.

Many emotional and physical symptoms occur as a result of invasive surgical procedures. Sadness and loss is often expressed related to changes in body image. Concern about the impending pathology report or uncertainties about upcoming therapies are also common fears (Crane-Okada & Loney, 2007). Post-operative recovery is focused on wound care and remobilization of the affected arm. Many physical symptoms or complications can result, which include impaired wound healing, infection, nerve injury, lymphedema, shoulder dysfunction, or phantom pain (Crane-Okada & Loney, 2007, NCCN, 2014). Dressing changes, early ambulation, management of drains, post-surgical exercises, and arm care are all necessary physical needs of women post-surgery (Crane-Okada & Loney, 2007).

Chemotherapy. In high-risk or lymph node positive IBC, chemotherapy will follow the surgical procedure and plays an important role in sustaining long-term disease free survival (NCCN, 2014). Combination chemotherapy +/- biologic therapy will be required. The chemotherapy regimens are scheduled monthly for four to eight months and if biologic therapy is required is it extended to an additional year of treatment (NCCN, 2014). The chemotherapy regimens that are used for low, intermediate and high risk breast cancers are illustrated in Appendix D. There are sixteen rural community cancer locations across the province of Manitoba, including the Brandon Western MB Cancer Center (CCMB, 2000). Breast cancer systemic therapy and associative care is managed in the community sites. After review and evaluation with a medical oncologist in Winnipeg treatment plans are established and the therapy is initiated in the rural CCP under the direction of the oncologist.

Systemic and biologic therapy has many challenges that require clinical expertise and professional management. Each drug has specific side effects or relevant clinical toxicity and each person's response to therapy will vary. Many needs, not just physical, that affect an

individual in every domain of the supportive care framework occur. Many women will need ongoing relevant information, emotional support, professional intervention, and astute symptom management (Fitch, 2009). The needs are complex and require tailored interventional support based on the individual experience. An added dimension of complexity occurs while living away from the oncology expertise in the management of treatment-related problems. Trained oncology nurses and family doctors are positioned in CCP sites but some ongoing challenges continue to exist related to isolation, relocation, and access to resources or managing oncology-related emergencies (Dr. M. Bruno, Family Physician in Oncology, Pinawa CCP, personal communication, February 14, 2014).

Radiotherapy. Involved-field, external beam radiation is the next phase of the treatment plan for IBC. Radiation has an important role in combination with these other therapies to prevent local recurrence (Crane-Okada & Loney, 2007, NCCN, 2014). Radiation targets the chest wall, mastectomy scar, and nodal regions and will commence soon after the completion of systemic therapy. Once a treatment plan is established by a radiation oncologist the therapy will continue daily for up to 30 treatments (Crane-Okada & Loney, 2007, NCCN, 2014). Radiation therapy can only be delivered in Winnipeg or Brandon. Therefore, women in this province living with breast cancer will need to relocate to an urban center for care. Wait times for breast cancer radiation are approximately two to four weeks (Government of MB, n.d.) Women are often provided with some notice when a machine becomes available and are required to make travel arrangement and find accommodation while they relocate to an urban site.

Radiation to the chest wall and nodal regions has its own associative challenges and toxicities. Skin changes, fatigue, pain in the radiation field, anorexia, sore throat, and persistent cough are some of the problems that can occur in the first few weeks. Pulmonary changes,

cardiac abnormalities, chronic lymphedema, or secondary malignancies are potential late stage effects from the treatment (Crane-Okada & Loney, 2007). Similar to the other treatment modalities the needs of a woman undergoing radiation therapy are complex requiring supportive care and ongoing symptom management for months to years following therapy depending on the associative toxicity.

Hormone Therapy. Aromatase inhibitors are a pharmacologic class of drugs representing first-line hormone treatment for hormone receptor-positive post-menopausal women with breast cancer (Deglin & Vallerand, 2003). These drugs reduce or block the action of estrogen in women which is thought to stimulate breast cancer growth. Long-term hormone therapy is an indication in a majority of cases based on the individual pathology (Langhorne et al. 2007). Other estrogen receptor modulators may be prescribed based on pathology, tolerance, or menopause status (Langhorne et. al., 2007). The drugs are usually prescribed orally for 5-10 years but occasionally intramuscular or subcutaneous therapy may also be indicated in the pre-menopausal population (British Columbia [BC] Cancer 2011a). Many side effects or problems can occur from these medications which include edema, fatigue, hot flashes, weight gain, hypercholesterolemia, osteoporosis, arthralgia, myalgia, headache, bone pain, sweating, and depression (BC Cancer 2011a; 20011b; 2015d). Additionally, long-term exposure to the medications can increase the risk of secondary uterine malignancies and therefore close gynecologic follow-up will be required (BC Cancer 2015d). The long-term duration of this treatment can have a marked impact on the quality of life of individual receiving therapy in every aspect of their life. The treatment modality was not thoroughly explored in this study as many of the women were just starting the therapy at the time of their interviews.

Surveillance and Follow-up

Five-year relative survival for Stage II disease is 86% and Stage III disease is 57% (CCS, 2014). The transition from active care to survivorship care is a complex and emotionally difficult time for women (Miller, 2007). Treatment completion does not signal the end of care as ongoing chronic conditions, adverse long term effects to treatment, or late symptom management may be required. Rehabilitation challenges and confronting permanent physical changes can often create role or work-related challenges. Fear of relapse or uncertainty about the future can also be mounting concerns. Supportive care resources should cross all phases of the illness experience and not end at the completion of therapy (Fitch, 2009). Women will be followed for disease recurrence every 4-6 months for the first five years after completion of therapy. This will include a variety of tests such as mammography, blood work, chest x-ray, and physical examinations (NCCN, 2014). At this point in the treatment trajectory the women are often referred back to their family physicians to manage their follow-up care. This phase of illness was not thoroughly explored in this study but some challenges will be illustrated with this transition process.

Supportive Care Needs of Women Living with Breast Cancer

The following section features the supportive care needs that are specific to all women living with breast cancer. Additional supportive care challenges that women face while living in rural areas has also been highlighted. Supportive care needs will be described according to the supportive care framework (Fitch, 2009) under the following domains including physical, informational, social, practical, emotional, psychological, and spiritual domains.

Physical Domain

Complex multi-modality treatment regimens for IBC have associated side effects, toxicity, and long-term complications that are specific to each mode of therapy (Crane-Okada &

Loney, 2007). Surgery, chemotherapy, radiation, biologic therapy, and long-term hormone treatment all present unique physical challenges that affect one's usual day-to-day functioning. The need for physical comfort, freedom from pain, and optimal nutrition are the foundational necessities of the physical domain. During any stage of the cancer experience amelioration or reduction in physical symptoms is the primary goal of care (Fitch, 2009). Symptom management of cancer-related problems and treatment-related toxicity is an integral role of the nurse (CANO, 2001; Langhorne et al., 2007). Management of symptoms, such as pain, nausea, vomiting, fatigue, weakness, anorexia, changes in bowel habits, alopecia, shortness of breath, weight changes, neuropathies, sleep disturbances, mucositis, and bone marrow suppression are common symptoms that directly impact the quality of life of the individuals living with many cancers (BC Cancer Agency 2013a, 2015a, 2015b, 2015c; Langhorne et al., 2007, NCCN, 2013). Long-term toxicity and/or late complications will add to complexity of the cancer experience. These may include and not limited to cardiomyopathy, pulmonary fibrosis, pneumonitis, osteoporosis, or secondary malignancies (BC Cancer Agency 2013a, 2015a, 2015b, 2015c; Langhorne et al., 2007; NCCN, 2014). Many of these symptoms and complications are the realities facing women living with breast cancer.

The physical needs must be measured based on individualized response to the various treatments and status of the illness (Langhorne et al., 2007). Therefore, it is difficult to articulate all the possible physical symptoms that could occur. However, some commonly reported physical symptoms do exist that are specific to breast cancer. Lymphedema, limited mobility to the affected arm, impaired sexual functioning, menopausal symptoms, and phantom breast pain are frequently reported in the literature (Crane-Okada & Loney, 2007; Schmid-Buchi, Halfens, Muller, Dassen, & van den Borne, 2013; Wilkes, White, Beale, Cole & Tracy 1999). Other

reported physical symptoms include weight changes, body image disturbances, skin changes, fatigue, and impairment to activity of daily functioning (Crane-Okada & Loney, 2007; McGarry, Ward, Garrod, Marsden, 2013). Each treatment modality also has distinguishing physical ailments that are a direct result of therapy. Surgery can cause side effects such as pain, weakness, and limited mobility. Chemotherapy frequently causes alopecia, myelosuppression, fatigue, and mucositis. Radiation promotes skin reactions causing pain. Finally, hormone therapy often exacerbates menopausal symptoms, or bone pain (Crane-Okada & Loney, 2007). These are a few examples to illustrate the scope of physical problems that could result from breast cancer therapies.

The literature also reveals that travel can markedly exacerbate physical symptoms. Additionally, lack of access to health services or other supportive resources can further impact the physical needs of individuals living with cancer in rural areas (Fitch et al., 2003; Hegney, Pearce, Rogers-Clark, Martin-McDonald & Buikstra, 2005; Girgis, Boyes, Sanson-Fisher, & Burrows, 2000). Moreover, feeling unprepared to care for complex physical symptoms can be overwhelming for individuals and their families when they live in rural or remote areas because of limited access to services (Loughery & Woodgate, 2015). The women who participated in this study described their physical symptoms from presentation of illness and throughout the treatment trajectory. Furthermore, the impact living rurally on the physical domain was also described and will be highlighted in the presentation of findings.

Informational Domain

The operational description of this domain is defined as needs related to information required during the cancer trajectory (Fitch, 2009). The outcomes of informational supportive care should focus on reducing confusion, anxiety and fear, supporting the individual and their

family in the informed decision-making process, and provide guidance in skill acquisition. Therefore, it is imperative to provide information regarding the various treatment modalities, tests, procedures, side effects and management of symptoms, physical care of devices, and potential complications of treatment. Additionally, availability of supportive services, educational resources, or other care processes should also be made available. Accordingly, this domain is directly related to access to professional assistance and expert oncology practitioners so individuals can obtain the desired information and services required to make informed decisions (Canadian Nurses Association [CNA], 2008; Fitch, 2009).

The informational needs of breast cancer patients are complex. Many learning needs exist that can change day-to-day during the cancer journey (Bastable, Gramet, Jacobs, & Sopczyk, 2011; Crane-Okada & Loney, 2007). Informational needs can be categorized according to three domains of learning (Bastable et al., 2011). Cognitive learning needs includes information regarding prognosis, tests and procedures, various treatment modalities and associative toxicity, management of symptoms, and long term complications. In the psychomotor domain, a woman may need information on the care of a central venous catheter, administration of a subcutaneous injection, or application of a compression stocking to manage lymphedema. Fear of a new diagnosis, disruptions in family life, or learning to live with changes in body image may encompass an affective learning discussion (Bastable et al., 2011; Crane-Okada & Loney, 2007). Different levels of complexity associated with each learning need must be considered directly related to the complex level of learning required when faced with a cancer diagnosis. Furthermore, many variables exist in the teaching learning process that can impede or enhance someone's ability to learn. Obstacles to learning may include high anxiety levels, literacy, cultural beliefs, cognitive ability, or complexity of task. Incentives to learning may include

motivation, support systems, level of aspiration, gender, or past experience (Bastable et al., 2011). The informational needs of women undergoing breast cancer treatments are multifaceted and many variables need to be considered based on the teaching and learning literature.

Considering the complexity of the cancer experience, informational needs of women living in rural areas are multifaceted. A systematic review by Fiszer, Dolbeault, Sultan and Bredart (2014) featured twenty-three quantitative articles that analyzed the unmet supportive care needs of breast cancer patients and survivors. Key objectives of the study were to measure prevalence, intensity, and predictors of unmet supportive care needs. The most frequently reported unmet needs from the studies included being informed about things you can do to get well, having a HCP to talk to about their concerns, being informed about test results as soon as possible, and being informed about the benefits and side effects of treatments. The authors concluded that supportive care needs of breast cancer patients and survivors touch upon many domains and in every aspect of care. Variables related to individual characteristics such as cultural, demographic, emotional, or psychosocial factored in which is consistent with the teaching and learning literature (Bastable et al., 2011; Fiszer et al., 2013). An alternative study (Au et al., 2012), featured a mixed-method research study investigating the type and extent of unmet needs in Chinese women with advanced stage breast cancer. This study featured 198 women who participated in face-to-face interviews and completed a needs survey. The sample included women with first time diagnosis (56%), recurrence diagnosis (43%), locally advanced (47%), and metastatic disease (53%). The authors found that needs related to access to health systems and other patient support were the most frequently reported unmet needs. Being informed about the cancer, management of illness, status of cancer, and explanation of test results were other important needs identified in the study. Additionally, being provided with

written information about the illness and treatment was also important. Interestingly, the authors also discovered that the information needs of women did not widely vary based on stage of illness with the exception of women who were newly diagnosed when informational needs are heightened (Au et al., 2012) These studies contribute to a body of knowledge which illustrate the importance of informational support as an ongoing need throughout the breast cancer journey.

Challenges also exist related to living in rural setting that markedly affects the informational domain. Service provision challenges, lack of access to qualified HCP, and isolation from professional support is frequently reported in the literature (McGrath, 2001; Rogers-Clark, 2002; Wilkes, White, & Riordan, 2000; Wilkes, White et al., 2006). Limited access to support groups, supportive services, and homecare is also described (Loughery & Woodgate, 2015) Additionally, challenges retaining family doctors who have experience in cancer-related problems also complicate the informational support needed by rural people living with cancer (Loughery & Woodgate, 2015; Rogers-Clark, 2002; Wilkes et. al., 2000; Wilkes et. al., 2006). The informational needs of the women have been explored throughout their treatment journey and specific rural challenges have also been featured in the finding section of this study.

Social Domain

Social support is described as the perception or reality that one is cared for, has assistance from others, and is part of a social network (Pender, Mudargh & Parson, 2011). Support can be both tangible and intangible. Levels of support may include emotional, affirmational, informational, or instrumental support. Additionally, support can be received from many different avenues which include family, friends, peers, community, religious affiliations, health care professionals, or self-help groups (Pender et al., 2011).

A cancer diagnosis can affect a person at many levels of the social spectrum. Needs related to family relationships, changes in family or work-related roles, community engagement, and extended societal relationships will impact a person when faced with a cancer diagnosis (Fitch, 2009). The social aspect of cancer can involve the immediate or extended family, close-knit neighborhood groups, and the wider community (Duggleby et al., 2010; Rogers-Clark, 2002). Alternatively, challenges related to lack of privacy, feelings of isolation, and difficulties finding the appropriate support or support groups can also complicate the cancer experience (Gray et al., 2004; Rogers-Clark, 2002). Establishing supportive networks with others in similar situations can play a role in the cancer experience. Enhancing self-efficacy and utilizing functions such as vicarious experience and verbal persuasion is a powerful tool in the management of supportive roles in the cancer experience (Bandura, 1982, 1993, 1994; Bastable et al., 2011). Peer support can help validate the experience and serve as an immense source of emotional support (Fitch et al., 2003; Gray et al., 2004; Hegney et al., 2005; Wilkes et al., 2006). The role of social support in health is widely documented in the literature. Positive supportive networks play a role in improving health outcomes, decreasing physical and mental illness, and reducing mortality rates (Callahan & Morrissey, 1993). Many support and advocacy programs exist for women living with breast cancer in this province. These resources will be outlined in the concluding section of this literature review.

Age is a critical risk factor to the development of breast cancer. Many women who are diagnosed will be in middle or older adult developmental stage of life. When a person reaches the older adult phase of development many additional psychosocial tasks must be anticipated (Bastable et al., 2011). The realities of aging, reconciling past failures with present and future concerns, or developing a sense of purpose for the remaining years of life are common realities

of aging people. Other psychosocial changes also occur during this time which includes retirement; illness or death of spouse; change in relationships; children, grandchildren and friends moving away; or relocation to an unfamiliar environment such as a senior residential living center. Illness during this period of a person's life can lead to depression, grief, loneliness, and isolation (Bastable et al., 2011). Major disruptions in social support, roles, and social relationships could inevitably be additional challenges for women at this development stage in life. A study by Yoo and colleagues (2010) featured 47 older women, ages 65-83, who participated in in-depth qualitative interviews with the purpose to explore the impact of breast cancer and their need for social support. Increased dependence and burden on others was a major fear for the women interviewed. This unavoidably increased their feeling of vulnerability. Lack of supportive networks outside the family unit or reluctance to seek assistance from non-family members was an additional concern. The side effects of chemotherapy and other competing chronic conditions compounded the need to ask for additional help which led to this increased feeling of dependency and vulnerability. Alternatively, women reported that support from other breast cancer survivors, religious affiliations, and professional support was very comforting (Yoo, Levine, Aviv, Ewing & Au, 2010). The cancer journey is long and difficult. The social aspect of cancer is directly linked to the concept of support and supportive roles at many different levels. The need for support and positive social relationships assists in coping and adaptation to any cancer experience (Fitch, 2009).

The culture of rural life is often viewed very positively. People often choose to live in rural setting based on extensions of supports and close-knit ties in the community (Duggleby et al., 2010; Rogers-Clark, 2002; Winters & Lee, 2010). Alternatively, lack of privacy or anonymity is also reported in the literature and when faced with illness and can become very

isolating (Gray et al., 2004; Rogers-Clark, 2002; Winter & Lee, 2010). A qualitative study by Rogers-Clark (2002), focused on rural women living with breast cancer. The findings from the study highlighted both positive and negative aspects of rural life. The close-knit communities offered opportunities for significant emotional support. Alternatively, living away from specialist, disruptions to family life when relocated for treatment, isolation and lack of privacy were also significant challenges. The authors concluded that many complex variables need to be considered when faced with illness in rural settings and tailoring intervention accordingly is warranted. All the women who participated in this study were asked to describe their supportive networks and the impact of support from a rural perspective was also thoroughly explored.

Practical Domain

The practical domain relates to the need for direct assistance with the activities of daily living or instrumental activities of daily living (Fitch, 2009). Activities of daily living (ADL) can be categorized as bathing, dressing, mouth care, dietary intake, ambulation, mental status, and bowel and bladder elimination (Miller, 2012). Many of these basic needs will be affected when going through cancer treatment and can markedly affect both the practical and physical domain (Crane-Okada & Loney, 2007). Instrumental activities of daily living (IADL) can be categorized as meal preparation, grocery shopping, telephone use, transportation, medication administration, laundry, and money management (Miller, 2012). When faced with a cancer diagnosis many increased demands can impact day-to-day life. Additional practical needs associated with the cancer experience encompass a broad range of tasks, such as the need for daily help at home, travel to and from treatment facilities, employment issues, finances, child care, housing, shopping, or legal needs. These needs will vary from person to person and depends on the age of the individual, family and financial situation (Fitch, 2009).

Maintaining daily responsibilities at home and work while undergoing cancer treatment can be challenging for patients and another noteworthy practical need that can affect a women living with breast cancer. Fatigue is the most frequent complaint for all persons living with cancer and can be one of the most distressing symptoms which markedly affect daily life (Crane-Okada & Loney, 2007; McGarry et al., 2013; Schmid-Buchi et al., 2013; Wilson, 2007). Anemia, cachexia, metabolic disturbances, sleep disturbances, or infection can contribute to extreme fatigue. Additionally, disease or treatment-related factors, psychological distress, or inactivity are significant risk factors to the development of fatigue (Wilson, 2007). The consequences of cancer-related fatigue are directly related to functional status and the inability to engage in a wide variety of usual daily activities (Wilson, 2007). Basic ADL both including daily care and instrumental tasks can be impacted dramatically when going through breast cancer treatments (Crane-Okada & Loney, 2007). Additionally, rural people living with cancer also have the additional burden of long travel days and frequent commutes to the city which can further escalate the fatigue and disrupt everyday life (Martin-McDonald et al., 2003; McGrath, 2001). Based on this data, day-to-day practical needs of a women living with breast cancer can be markedly affected and can vary at any time during the cancer trajectory.

When considering the practical needs of cancer patients, the hidden costs of cancer care must be considered (Wagner & Lacey, 2003). Out-of-pocket costs may include travel, parking, food, lodging, child or elder care, housekeeping assistance, prostheses, and other assistive devices. Transportation is frequently seen as a noteworthy source of out-of-pocket expenses and a hurdle to many persons living with cancer (Wagner & Lacey, 2003). Subsequently, financial implications of cancer place an enormous burden on all persons living with cancer. A dramatic decline in family income due to disability and the rising out-of-pocket expenses associated with a

cancer diagnosis can contribute to significant financial hardship from which some families never recuperate (CCS, 2013b). Rural residents who need to travel for medical treatments are at the greatest risk of financial devastation related to additional travel and relocation expenses (CCS, 2013b). Many other out-of-pocket expenses that directly affect rural people living with cancer may include wear and tear on the family vehicle, maintenance of two households, additional childcare, long distance calling, or meals in restaurants (Hegney et al. 2005; Fitch et al., 2003). When considering the long and enduring treatment that a woman with IBC will undergo, the financial implications of living rurally will be a significant variable that requires attention. As previously discussed, women at this age will be nearing retirement or experiencing age-related psychosocial life changes, such as death of a spouse. This will also need to be factored in when considering the financial implication of a diagnosis of this magnitude.

The burden of travel and relocation for rural people living with cancer is a noteworthy finding in the scholarly literature. Travel preparation or finding someone to assist with the driving responsibilities can be a mounting challenge. Organizing medical appointment or diagnostic tests around travel is another concern. Additionally, poor driving conditions, busy urban traffic, navigating the city, extensive travel days, or arranging accommodations when relocated are other noteworthy findings in the literature (Fitch, 2003; Girgis et al., 2000; Gray et al. 2004; Hegney et al., 2005; Wilkes et al., 2000; Wilkes et al., 2006). The impact of travel can significantly alter the cancer experience but is even more disturbing when treatments decisions are made based on decisions not to travel (Celaya et al., 2006; Punglia et al., 2006). In the quantitative study by Punglia and colleagues (2006), the authors looked at distance to the radiation treatment facility and the use of post-mastectomy radiotherapy in breast cancer patients (n=19,787). The authors found there was a direct correlation between increase travel distance

greater than 75 miles and not completing the therapy (Punglia et al., 2006). In a second study, by Celaya and colleagues (2006), the authors reviewed the effect of winter driving on the use of radiation therapy in the breast cancer population and found that women were less likely to complete therapy when weather conditions were poor (Celaya et al., 2006). Variables such as long travel days or poor weather conditions were important study findings and will be featured in the description of findings.

Emotional Domain

The emotional domain is characterized by a sense of belonging, comfort, and understanding that exists during times of vulnerability (Fitch, 2009). Some feelings that may occur in this domain may include distress, anxiety, depression, anger, guilt, grief, abandonment, hopelessness, powerlessness, uncertainty, shame, or isolation (Fitch, 2009; Langhorne et al. 2007). In a quantitative study conducted by Au and colleagues (2012), many unmet emotional needs of Chinese women living with breast cancer were identified. Women reported feelings of anxiety, depression, uncertainty, fear, sadness, and worry. Additionally, acknowledgement or validation of feelings and information from the HCP was directly linked to the emotional wellness of the women participating in the study (Au et al., 2012). In an alternative study, conducted by McGarry and colleagues (2013) the authors explored unmet needs featuring n=101 breast cancer patients. Altered body image and physical changes were the most frequently reported unmet needs for the women. Fatigue, weight gain, disappointment with reconstruction, pain, hair loss, nail changes, and lymphedema are common occurrences. The authors also found there was a correlation between how the women were feeling physically and their emotional wellbeing. They concluded that emotional adjustment to illness was very dependent on meeting all the unmet needs that women will experience (McGarry et al., 2013). Fear is another common

reaction to a cancer diagnosis. Fear of physical outcomes, treatment, changes in quality of life, separation from loved ones, and recurrence are reported in the literature (Burman & Weiner, 1997; Ellegaard, Grau, Zachariae & Jensen, 2017; McGinty, Small, Laronga & Jacobsen, 2016; Thewes, Lebel, Leclari, & Butow, 2016). The emotional journey with cancer comes with many complex emotions and therefore the need for comfort, belonging, understanding, and reassurance is necessary for all persons living with cancer (Fitch, 2009).

Emotional distress is an expected response to all persons living with cancer (Fitch, 2009). Levels of distress can be heightened at different points of time in the cancer journey such as in the diagnostic phase or with a new diagnosis (Brocken, Prins, Dekhuijzen, van der Heijden, 2012; Costa-Requena, Rodriguez & Fernandez-Ortega, 2012). Additionally, distress can also escalate at times of diagnostic testing such as follow-up mammography (McGinty et al., 2016). Therefore, all persons living with cancer require some level of emotional support to validate their concerns. The level of support varies from person to person and treatment to treatment. Some people can mobilize their own resources to foster effective coping whereas others may not be able to find ways to meet their emotional needs. This can escalate the emotional distress they are already experiencing which can compromise adherence or increase utilization of health care services (Fitch, 2009). Person living in rural areas may also have the additional obstacle with access to healthcare supports or services as previously note in this review. Therefore, attention will be required to explore supports and services available in rural areas that assist in fostering the emotional wellbeing of women living with breast from rural areas of the province.

Psychological Domain

The primary feature of the psychological domain is the ability to cope with the illness experience and its outcomes. The need for personal control and positive self-esteem creates

wellness in this domain (Fitch, 2009). Many challenges may occur which can affect a person psychologically when living with cancer. These may include changes in lifestyle, loss of self-esteem or control, sexual problems, diminished cognitive ability, self-image problems, body image changes, or fear of recurrence (Compas, & Luecken, 2002; Fitch, 2009, Langhorne et al., 2007). Heightened levels of negative emotions and psychological distress can often lead to escalated feelings of anxiety and depression (Compas & Luecken, 2002). Professional counseling, additional peer support, or support groups is often necessary to promote psychological wellness and therefore directly related to the social domain. Wellness in the psychological domain may depend on the support available and care received during the cancer experience (Fitch, 2009).

It is frequently noted in this review that many factors within all domains can affect adaptation and coping. This can have a direct impact on the psychological wellbeing of the person throughout the cancer journey. A survey study conducted by Schmid-Buchi and colleagues (2013) featured n=175 newly diagnosed women with breast cancer. The authors found that as unmet needs in any domain increased, vulnerability escalates, and needs in this domain are heightened. They concluded that most women required support to assist with psychological issues and in situations when there was lack of support or conflicts in personal relationships there is a higher demand for support. Without the appropriate support or attention from a HCP, psychosocial distress elevates and has a significant impact on quality of life and personal control (Schmid-Buchi et al. 2013). Rural people also have the additional challenge of lack of psychological and supportive services that might be available in their region which could directly impact the experience (McGrath, 2001; Rogers-Clark, 2002; Shepard, Goldstein, Olver & Parle, 2008; Wilkes et al., 2000; Wilkes et al., 2006). Alternatively, rural living is often

associated with extensions of supports and close-knit ties in the community which could foster psychological wellness (Duggleby et al., 2010; Rogers-Clark, 2002; Winters & Lee, 2010).

Therefore, attention to the all supportive needs of women living with breast cancer is imperative to facilitate psychological wellbeing and foster effective coping.

How a woman adjusts to the cancer experience is often directly related to a number of variables (Compas & Luecken, 2002). Characteristics of the disease, attributes of the person, social relationships or extension of resources, cognitive appraisal, and effective coping mechanisms all play a role in psychological adjustment and adaptation (Compas & Luecken, 2002). Personal attributes such as optimism, self-reliance, or resilience can foster effective coping (Compas & Luecken, 2002; Rogers-Clark, 2002; Roland & Baker, 2005; Winters & Lee, 2010). Additionally, utilizing effective coping skills such as seeking social support, positive reframing, reappraisal, emotional expression, religious/spiritual focused-intervention, avoidance, or distraction will also be utilized (Mehrabi, Hajian, Simbar, Hoshyari, & Zayeri, 2015). Women from different ethnicities, geographic location, education levels, or age may also use different strategies in different phases of the disease to help foster effective coping strategies (Compas & Luecken, 2002; Mehrabi et al., 2015). Therefore how a woman copes with this illness is multifaceted and many variables need to be considered.

Negative coping skills can also lead poor psychological adjustment to the illness. In a study by Hack and Degner (2004) the authors measured coping responses following a breast cancer diagnosis and its impact on psychological adjustment three years post diagnosis. The authors found that poor long-term psychological adjustment was directly related to effective coping skills early on in their treatment. Women who used coping skills such as avoidance, passive acceptance, and resignation were at a higher risk of ineffective coping and intervention

strategies should be implemented to better assist women as they are faced with the many challenges that are imposed on them (Hack & Degner, 2004). In an alternative study by Silva, Crespo and Caravarro (2012) the authors examined psychological adjustment of women living with breast cancer across all the phases of illness and found that the women were the most vulnerable and had higher feelings of anxiety in the surgery stage of illness. They concluded that promoting adaptive coping strategies early in the treatment journey was imperative (Silva et al., 2012). Therefore, many factors need to be considered when evaluating the psychological needs of women living with breast cancer. Additionally, how a woman adjusts to the illness experience at the various phases of illness also requires attention.

Spiritual Domain

Holistic patient care includes consideration of the spiritual needs of an individual (Swinton, Bain, Ingram & Hey, 2011). It is important to note that spirituality is not necessarily synonymous with religion and both concepts should be defined separately (Reynolds, 2006). Spirituality can be defined as a “dimension of a person that involves one’s relationship with self, others, the natural order, and a higher power manifested through creative expressions, familiar rituals, meaningful work, and religious practices” (Taylor, 2001, p. 177). It involves finding meaning to life and living life according to a set of values even in the face of illness. Religion can be defined as an “organized system of beliefs and identification with a religious community” (Taylor, 2001, p. 177). One might not be a part of a religious affiliation and still be very spiritual. Therefore, finding the purpose of life and spiritual wholeness are central dimension of this domain. Tasks may include searching for the meaning of life, re-examining values or priorities, reflecting on losses in life, or facing one’s own mortality (Fitch, 2009). When creating a spiritual assessment one can focus on four areas of life which include: connection with persons or

communities including feelings about self, faith, or relationships; meaning and joy including important features in life, proud, or happy moments; strength and comfort including sources of strength, past coping skills, dreams, or visions; and hope and concerns while reflecting on unfinished business or plans for the future (Taylor, 2001).

Spirituality can be a means of gaining a sense of control over a cancer diagnosis, decreasing stress or achieving inner peace (Reynolds, 2006). Alternatively, a cancer diagnosis can also trigger spiritual distress, existential despair, pain, and suffering (Fitch, 2009). In a grounded theory qualitative study, conducted by Halstead and Hull (2001) the authors examined the process of spiritual development in women diagnosed with cancer. Eight of the ten women in the study had a diagnosis of breast cancer. The authors found that the participants were able to find meaning in their belief system which was challenged by their diagnosis. A three-phase paradox was grounded in the data. The first phase included deciphering the meaning of cancer when faced with a new diagnosis of cancer. The level of distress affected their spirituality and questioned the meaning of life. Paradoxes in this phase included conflicting life challenges, feeling that their body let them down, concerns with the health care system, being unable to control the circumstances in their life, and personalizing mortality. The second phase involved realizing human limitations. When entering the treatment phase of illness the interrelatedness of physical, emotional, and spiritual aspects of care was remarkable. Paradoxes in this phase included dealing with role changes, changes in body image, and questioning God and faith. The third and final phase involved learning to live with uncertainty. Searching for the meaning of cancer was found to be a challenging task. Paradoxes in this phase included the cancer defining the person and facing the possibility of death. Spiritual attributes that the women used to guide them through the three phases included “thankfulness, peacefulness, enhanced meaning and

purpose, hope, connectedness, increased strength, trust, prayer, forgiveness, and assurance of God's presence" (Halstead & Hull, 2001, p. 1541). This study adds to a body of literature delineating the spiritual experience of women with a diagnosis of cancer (Meraviglia, 2006; Reynolds, 2006; Swinton et al., 2011 Taylor, 2001). These concepts and attributes mentioned formed the basis for exploring the spiritual needs of women living with breast cancer in this study. This further demonstrates the value of spiritual intervention that should be considered in the care of persons living with cancer. Spiritual wellness can contribute to positive patient outcomes and enhanced well-being.

It becomes clear from this part of the review that needs in all the domain of the supportive care framework will be markedly affected during the illness experience. Moreover, inter-relationships will exist amongst the domains or aggravated by unmet needs in other domains. Additionally, unique challenges occur based on the existing literature for rural women living with breast cancer that are unique to this population. Supportive care should be provided to all people with cancer and their families throughout the patient pathway, from pre-diagnosis and onwards. It should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment (Fitch, 2009; National Institute for Clinical Excellence [NICE], 2004).

Supportive Care

The following section will feature a description of supportive care services and rural supportive care initiatives available for persons living with cancer based on the national and international review of empirical rural literature.

Supportive Care Services

The aim of service delivery models for supportive care is to ensure that the patient with cancer and their family receive the support they need to help them cope with illness and its treatment (Fitch, 2009; NICE, 2004). In addition to receiving the best possible treatment options patients and families also require; to be treated as individuals and have their voice heard; high quality, timely information at all stages of the patient journey to assist in the informed decision making process; well-coordinated, face-to-face communication with the interdisciplinary health care teams; supportive care options and resources available to them; proper management of physical symptoms; emotional and spiritual support for the patient and members of the family; and financial and practical support or advice as required (NICE, 2004).

Provision of supportive care will help to maximize the benefits of treatment and support the patient to live as well as possible with the effects of disease and treatments (NICE, 2004). Joint participation with the patient and health care team in addition to astute, individualized assessment, and coordination of care is required (Fitch, 2009; NICE, 2004). Supportive care should encompass self-help and access to supportive networks, information giving, psychological support, symptom control, rehabilitation and survivorship programs, complementary therapies, and spiritual support (NICE, 2004). The scope of supportive care will exist at many levels. Health care providers at teaching hospitals, ambulatory cancer centers, community hospitals, or primary health care clinics play a role in the supportive care journey. Interdisciplinary teams including oncology physicians and nurses, pharmacists, family doctors, occupational therapist, physiotherapists, psychosocial oncology, spiritual care, dieticians, or visiting home care nurses have active roles. Advocacy groups such CCS, driver programs, or other not-for-profit organizations provide different services for different needs. At the community level extended friends, family, neighbors, community members, religious affiliations,

employer, or colleagues can play a role in providing assistance when needed. Self-help groups, support groups, on-line blogs, or peer support groups may also play a role. Many on-line informational resources are actively and readily available with the new and evolving age of informatics (Stacey, Fiset, Ellis, Fothergill-Boubonnais, 2009). Individualized ongoing assessment of the supportive care needs is required and should be adapted to each unique circumstance.

Supportive care program guidelines features a framework for ensuring supportive care needs are properly addressed across the cancer spectrum (Fitch et al., 2009). In the informational domain standardized informational packages should be created and easily accessible through multiple avenues. This information should consider language, readability, comprehension, and culture. Other alternative or complementary therapies should be included as an additional therapeutic option (Fitch et al., 2009). In the physical domain, amelioration or reduction of symptoms is an important aspect of care. Access to appropriate health care providers and services are required to ensure adequate pain and symptom management is achieved (Crane-Okada & Loney, 2007; Fitch, 2009). Spiritual support and counseling while considering specific religious needs should be explored. Peer, community, or professional supports should be offered. Practical needs based on legal requirements, disability options, financial considerations, funding sources as well as day-to-day needs should be also considered and implemented accordingly (Fitch et al., 2009).

Rural Supportive Care Services

The Calman-Hine report (1995) outlined a radical reform of the United Kingdom's (UK) cancer services with the aim of improving outcomes and reducing inequalities for all persons living with cancer. The guiding principles behind this important document included: all patients

should have access to high quality care in a community or hospital despite where they live; care should be provided as close as home as possible; expansion of public awareness and national screening programs should be enhanced; ongoing communication, information and support should be provided to the patient and family throughout the cancer journey; psychosocial support is required at all stages of the cancer experience; and careful monitoring of treatment outcomes and management of cancer symptoms is required (Calman-Hine, 1995). Prior to this report centralization of cancer service was the standard of care in many areas of the world. Based on these guidelines a new structure of cancer care service provision was proposed in the UK which highlighted three levels of cancer service provision which includes primary care, regional and designed cancer centers. The designed cancer centers provide the overarching cancer expertise to community centers and primary care practitioners' while a shared model of care is implemented. Integration of cancer services utilizing this model of care minimizes travel time while maintaining high quality expertise and mentorship and utilizes local resources and standardized protocols (Calman-Hine, 1995). Since the release of this report, many countries across the globe have adopted the Calman-Hine approach to care (Adams et al., 2009).

Centralization of specialized oncology care is situated in most major metropolitan centers. To promote continuity and integration of healthcare services to meet the special demands of populations in rural areas other emerging programs have been implemented. Integrated and managed care pathways, outreach chemotherapy programs, shared care models of service delivery, integration of primary care, increase use of teleoncology, patient navigation programs, expansion of psychosocial oncology, and improving access to on-line resources are strategies being implement in national and international settings (Adam et al., 2009).

To illustrate this emerging model of care the British Columbia (BC) cancer system will be described as an exemplar. British Columbia has a population of approximately 4.6 million people across a geographically vast and diverse province (Carlow, 2000). The BC Cancer Agency governs the BC Cancer System and includes a network of services: a major cancer research center located in a large urban setting; six comprehensive regional cancer centers strategically located across the province; nineteen co-managed systemic therapy clinics; provincial programs in radiation, systemic and surgical oncology; provincial programs in cancer rehabilitation and palliative care; provincial breast cancer screening programs with over 30 sites and mobile ultrasound units; a provincial cervical cytology program; regional colposcopy clinics and consultative primary care outreach clinics in locations across the province (Adam et al., 2009; Carlow, 2000; BC Cancer Agency, 2013b). Each regional cancer center provides: patient assessment, diagnostic and therapy planning; radiation therapy; chemotherapy services; nursing care; patient and family counselling; nutrition counselling; pharmacy services; pain and symptom control service; teaching and applied research activities; and a cancer information library (Adams et al., 2009). In addition, BC Cancer agency has a comprehensive website which includes many on-line resources for HCP and patients. Educational resources are available on this site which include a comprehensive breast cancer video-taped series entitled 'Closer to Home' which features taped sessions on fatigue, lymphedema and arm exercises, nutrition, side-effects of chemotherapy and radiation, and recovery post-breast reconstruction. British Columbia has also incorporated patient navigation programs, teleoncology, and expanded psychosocial oncology across the province into their overall plan (BC Cancer Agency, 2013b). Additionally, BC has four affordable accommodation services situated near the primary cancer centers for person who need to commute for care. These services are provincially funded and supported by

CCS, BC. Most of the provinces in Canada have formally structured cancer control agencies or governing bodies similar to the BC structure. Although resources and services may be different based on population of each province the overall philosophy, mission and visions remain the same and is consistent with the Calman-Hine model of care (Calman-Hine, 1995; Carlow, 2000). In Ontario, for example, 14 regional cancer centers are situated across the province based on the significant population in this province. Access to expert oncology professionals and service is planned based on diffuse distribution of people across this province (CancerCare Ontario [CCON], 2014).

Conversely, Australia which is as geographically vast and populated as Canada has similar rural service delivery challenges yet each region of the country has adopted a slightly different approach to care (Clinical Oncological Society of Australia [COSA], 2006). In most of the regions of the country, the comprehensive cancer units are located in major metropolitan areas, such as Melbourne or Sidney. These centers consist of full range of service and high level expertise, such head and neck oncology, pediatric oncology, complicated gynecological or breast cancer treatments, brachytherapy, and hematological oncology including stem cell transplantation. Different levels of care exist in other areas of the country and vary from region to region. Care may be performed in a hospital, clinic, or outreach center. In addition, care may be integrated with other disease conditions such as cardiac disease or sleep disorders. A level one center may be described as prevention, screening and diagnosis only, level two may include chemotherapy, and level three-five will include varying degrees of treatment including radiation or simple surgery (Adams et al., 2009; COSA, 2006). Some of the emerging rural initiatives for supportive care that are featured in the Australia literature are similar to the work that is occurring in Canada. Initiatives such as increasing cancer nurse coordinators, aboriginal care

coordinators, psycho-oncology support, teleoncology, patient support activities, and integrative regional cancer transportation and accommodation services are underway. As well, expansion of the use of primary care in oncology, shared-care mentorship, and educational up-grading for rural generalist are identified as priorities (Adams et al., 2009; COSA, 2006). Another interesting finding in the Australia literature was over 50% of patients with a cancer diagnosis in Australia will receive radiotherapy treatments. This is thought to be related to the high incidence of malignant melanoma in this country. Initiatives are underway to expand radiation in rural areas, arrange distant planning, and out-reach consultant clinics with the radiation team. This is an effort to improve efficiencies, patient care, and decrease wait times for treatment (COSA, 2006).

Supportive Care Services in Manitoba for Women Living with Breast Cancer

Manitoba has adopted a similar model of care to the initiatives in other areas of the country and the world. CancerCare MB, located in Winnipeg, is the center of excellence for oncology service in our province. Interdisciplinary model of care is available to support a woman through the cancer journey. Expert disease site group clinics offer the substantive expertise which includes diagnostic and treatment options as well as follow-up and long term care. Expert practitioners are available to provide the informational, physical and emotional supportive needs as required. Breast disease site group nurses are situated in the surgical, medical, and radiation clinics to assist in the coordination of other supportive needs as necessary. These nurses are available to triage cancer-related problems or answer question or concerns as they arise. An urgent care clinic has been recently been established to handle oncology-related emergencies. CancerCare MB has an active Patient and Family Support Services which includes psychosocial oncology, spiritual, dietary care services and informational resources. Many practical needs are

considered during consultation with these practitioners. A resource library is available on-site and many on-line resources can be accessed through the CCMB website. Other resources are available including wellness programs and various support or self-help groups. A newsletter is published on a monthly basis and distributed through the psychosocial oncology department featuring weekly education and supportive programming available to breast cancer patients. A list of accommodation resources are also provided to individuals who need to relocate to the city for care.

Breast Health Center is another comprehensive resource offered to women with breast cancer. This diagnostic center provides care to women with all benign and malignant breast conditions. Diagnostic procedures including ultrasound, ultrasound core biopsy, mammography, and stereotactic biopsies are performed at the center. Surgical oncology physicians and plastic surgeons are available for diagnosis and counselling and minor breast surgery can be performed on site (Winnipeg Regional Health Authority [WRHA], n.d. b). Major surgeries and reconstruction will occur at one of the major hospitals in Winnipeg. Additional staff at the Breast Health Center includes radiologists, nurses, physiotherapists, social workers, and dieticians. Lymphedema, nutritional and psychosocial counseling is available for all women referred to the center. Pre and post-operative educational sessions are provided on a weekly basis (WRHA, n.d. b). On-line education resources are available to support rural women in this province. A two-part educational series entitled 'A Journey: Before and after surgery' has been made available on the website. Other resources including preparing for surgery, chemotherapy before surgery and after breast surgery, and other supportive services are available on-line (WRHA, n.d. a). Additional resources which includes types of breast cancer, lymphedema management, activity and exercises, prosthesis, breast reconstruction, diagnostic procedures,

copied with breast cancer, nutrition and risk reduction, and hereditary information can be accessed (Susan Dennehy RN, Breast Health Centre, personal communication, November 28, 2014; WRHA, n.d. a).

The WCCH is another important service specifically designed to service women living with either gynecological or breast cancer. It is mandated to assist individuals who have been touched living with cancer by providing information, support and referral to supportive programming. Comprehensive libraries of breast cancer resources are available on-site. An extension of on-line educational resources and programming via telehealth technology has also been created. 'Our Voice' is a newsletter published by WCCH three times per year. Featured in this publication includes survivor stories, breast health updates, support group information, on-line breast cancer publications, recent published works, patient and family support services, community programs and events. This published newsletter reaches approximately 50% of rural breast cancer survivors. Supportive networks through an active advocacy program are available to women who are in need of additional support. Thoughtfully matched, peer to peer support is managed by the staff of WCCH. This is an active evolving program which provides social, emotional, and psychosocial support to women living with breast cancer across the province. A breast cancer navigator follows all breast cancer patients who are referred to this program from time of diagnosis, through treatment, and into long term follow-up. She provides ongoing education, referral, navigation services, and emotional support. In addition, she provides additional counselling regarding prosthesis and reconstruction options (CCMB, 2017; Lori Santoro, Nurse Navigator, WCCH, Personal communication, January 14, 2014).

Manitoba consists of five regional health authorities (RHA) including Northern Health Region (NHR), Prairie Mountain Health (PMH), Interlake Eastern Health Authority (IEHA),

Southern Health Sante Sud (SHSS) and Winnipeg/Churchill Regional Health Authority (WRHA) (Government of Manitoba, 2014). Service provision for breast cancer varies in different regions across the province. Surgical intervention for breast cancer is primarily done in Winnipeg. Some breast cancer surgical procedures will occur across the regions of the province depending on surgical expertise in the designated area. Brandon has general surgeons who perform extensive breast cancer surgery but do not offer reconstruction. If a woman does not proceed to reconstruction at the time of the original surgery, wait times for delayed reconstruction can exceed two years (Debbie McNairnay, Oncology Nurse Navigator, personal communication, November 28, 2014). Reconstruction options are only available in Winnipeg with initial consultation and discussion managed through Breast Health Center or surgical oncology clinics at CCMB (Susan Dennehy RN Breast Health Centre, personal communication, November 28, 2014). Community Cancer Programs started in the 1980's and has evolved to 16 programs across the regions which provide chemotherapy closer to home (Appendix E). Most adjuvant breast cancer systematic treatments (Appendix D) are managed by the CCP center. Each center is staffed by one or two oncology nurses and trained family physicians in oncology (FPO). Frequently FPO's are only available one or two day/week because of the demands of their busy primary health care practice. As well, many people in rural Manitoba may or may not have a CCP close by that they can access. Winnipeg and Brandon are the only sites where breast cancer radiotherapy can be facilitated. Women from rural areas will be required to commute to one of these cities for treatment. If a woman is not living in PMH, she will be required to locate to Winnipeg for her treatment (Debbie McNairnay, Oncology Nurse Navigator, personal communication, November 28, 2014).

Rural Nurse Navigator Services, extending nurse navigator and psychosocial oncology services in rural Manitoba, was an initiative was implemented in 2008. This project was funded by CCMB Foundation and directed by Patient and Family Support Services and CCP (CCMB, 2009). These regional cancer program hubs are strategically located in larger cities across the province including Thompson, The Pas, Dauphin, Brandon, Boundary Trails, Steinbach and Selkirk. The goal of this program is to ensure all cancer patients from all parts of the province receive timely and appropriate access to quality care and improved coordination of service provision. Each regional hub is staffed with a nurse navigator, psychosocial oncology clinician, and FPO (Megan McLeod, Supportive Care Coordinator, Community Cancer Programs Network, CCMB, personal communication, December 16, 2014).

Despite this extensive list of available resources and emerging rural delivery models, equitable access to health services in rural and remote communities is an enduring challenge and can create additional unmet needs for many cancer patients (Gray et al., 2004; Kulig & Williams, 2012). These challenges were explored in this study. Challenges vary from region to region based on the service provision and support services that are available in that area. Supportive services that were utilized by the women will be presented in the findings of this study.

Chapter Summary

Diagnosis and treatment for IBC is a long and difficult process. This review provides a summary of breast cancer from detection, treatment to survivorship phases of illness including common and individualized supportive care needs in each of the domains. In addition, some rural challenges have been highlighted from a critical review of the literature. Supportive care service provision in many regions of the country and international literature are comparable but it is clear from this review that rural initiatives are part of the strategic direction in many countries.

Manitoba breast cancer service has been outlined. While many services exist that extend into rural settings there continues to be fragmentation of oncology care for the rural population. Due to the limited research on the supportive care needs of rural women living with breast cancer in Canada, future studies are recommended to understand the additional burdens and unmet supportive care needs of women living with this illness in this country. The following chapter will present the methodological approach of this research study utilizing an interpretive descriptive qualitative research design.

Chapter Four: Methodology

This chapter provides a thorough description of the research methodology and methods that will be utilized in this qualitative study. Interpretive description is detailed and philosophical underpinnings are presented. A description of the study's research methods and procedures including sample selection and recruitment process, setting, data collection methods, and approach to data analysis is provided. Next, strategies that were utilized to achieve methodological rigour, credibility and ethical considerations are described. Lastly, risk and benefits for the participants are outlined.

Discussion of Chosen Methodology

The primary purpose of this qualitative study was to arrive at an increased understanding of the supportive care experiences of adult women requiring treatment for IBC and who reside in rural Manitoba. The women who participated in this study were best positioned to describe their experience from a lived perspective. In this study many questions were posed related to the human experience and practical applied recommendations were explored. The questions included; 1) What are the supportive care experiences of women living with IBC who require multi-modality treatment regimens and reside in rural Manitoba? 2) How do the supportive care experiences change from detection to the end of the treatment phase of illness specific to living in a rural setting? and 3) What recommendations could be made on how to improve the supportive care experiences of rural women living with breast cancer in the province? All of these questions are concerns of human science and explore ways to address real practice problems that are pertinent to people living with cancer in our province. Interpretive descriptive qualitative research was an appropriate methodology for this study. Interpretive description represents a foundation for nursing's theoretical structure and body of knowledge by

providing a basis to understand how people experience illness, what nursing can do to make a difference and subsequently impact lives of people living with illness (Thorne, Kirkham & MacDonald-Emes, 1997; Thorne et al., 2004). A description of the chosen methodology will be detailed in the following discussion.

Interpretive Descriptive Methodology

Applied disciplines, such as nursing, are often looking for ways to address real practice problems that are pertinent to people in their care. Often problems identified can be shared by a group of people who are in similar circumstances. A challenge in nursing practice is determining what experiences are shared by individuals living a similar experience and what is unique to each individual (Thorne et al., 1997). Traditional philosophic underpinnings of qualitative research are deeply rooted in specific descriptive modes of human science (Streubert & Carpenter, 2011). Phenomenology cuts across philosophic, sociologic and psychological disciplines; grounded theory is rooted in the precepts of symbolic interactionism and human social processes; and ethnography is based on anthropology and committed to the discovery of cultural knowledge (Streubert & Carpenter, 2011). Methodological variation is often discouraged beyond these traditional approaches and consequently nursing researchers are often seeking other methods to find practical solutions to solve unique clinical problems (Thorne, 2008; Thorne et al. 1997).

Nurse researchers must give thoughtful attention to theoretical traditions but recognize that human health and illness experience comprise common patterns and interactions between psychosocial and biologic phenomena that are complex in nature. These patterns represent the core of our disciplinary practice knowledge and intervention resulting from these common patterns should be individualized in the context of a particular circumstance (Thorne et al.

1997). The practice goals and assumed knowledge gained based on all sources of the available empirical evidence creates the context in which engagement with the data starts the interpretation process (Thorne, 2008). This methodology is intended to address specific needs in qualitative research conducted within applied health disciplines. It is designed to identify commonalities of experiences, while maintaining attention to individual variation in ways that can be applied clinically on a case by case basis (Hunt, 2009; Thorne et al., 1997).

Interpretive description is a smaller scale qualitative study. The primary purpose of interpretive description is to identify themes and patterns within subjective perceptions and therefore generate an interpretive description to inform practice (Thorne et al., 2004). The literature review helped the researcher draw conclusions on the current state of knowledge. The critical review of the current state of knowledge forms the basis to begin the analytic process and the interpretive lens of the researcher should be accessible throughout the report of findings (Thorne et al., 1997; Thorne et al., 2004). The researcher is positioned in the study within the ideas. It is important for the researcher to reflect on ideas, thoughts, and perceptions, or personal experiences in advance to maintain the integrity of the study. Therefore, the inductive reasoning process that generates the results is grounded in the data under review (Thorne, 2008). The philosophic underpinnings are the foundation of the study integrity and guide the design decisions.

Philosophical Underpinnings

Interpretive description is described as a non-categorical, inductive, analytic qualitative approach. In order to prevent “method slurring” with other qualitative approaches, distinctions between methodological approaches must be captured. Epistemological and methodological grounding for interpretive description is rooted in the interpretive naturalistic orientation and

“acknowledges the constructed and contextual experience of human illness experience and at the same time allow for shared realities” (Thorne et al., 1997, p. 172; Thorne et al., 2004, p.3).

Assumptions of this research study include (Thorne, 2008, p. 74):

1. The study was conducted in a naturalistic setting as possible. Comfort and the ethical rights of participants were considered at all times.
2. One of the fundamental sources of clinical insight is the value of subjective and experiential knowledge of the participants.
3. Human commonalities and individual expressions of variations need to be captured within a shared spirit of interest.
4. Time and context within the descriptions must be attended to but reflection on specific issues that are not bound by time and context must also be considered.
5. The essential nature of the inquiry and the socially constructed element to human experience cannot be considered separate.
6. Multiple constructed realities exist in the world of human experience. It must be recognized that these realities could contradict what is known.
7. An inseparable relationship exists between the participant and the researcher and during the object of inquiry they interact to influence on another.

These philosophical underpinnings ensure coherence that distinguishes interpretive description from other qualitative or blended descriptions (Thorne, 2008).

The methodology also informed the methods of this study. Sampling plan and size, data collection strategies, methods for analysis were developed with the goal to develop rich interpretive descriptions of the experiences. Through the words and stories of the participants’ rich meaningful data unfolded. In interpretive description, the researcher inductively and

iteratively was immersed in the data through the coding, sorting and organization of data process while trying to apprehend the overall picture with questions such as “what is happening here?” and “what am I learning about this?” It is at this point that the nurse researcher came to know the individual cases intimately, abstract common patterns and produce knowledge that can be applied in a practice setting (Thorne et al., 1007). During this process rich interpretive descriptions were produced. The following discussion will provided details surrounding the research methods and procedures.

Research Methods and Procedures

Selection of research methods in this study were developed based on underlying philosophical underpinnings, relationships between the ideas and experience, background theoretical, and experiential knowledge of the researcher and ultimate outcomes of the study (Thorne, 2008). The following section describes the research methods and procedures that were implemented. Sample selection and recruitment process, setting, data collection methods, and approach to data analysis that was utilized will be described.

Sample and Recruitment Process

Purposive sampling was utilized for this study. Participants were selected based on certain shared characteristics. Each of the women experienced a breast cancer journey while living in a rural area and provided a rich description of the phenomenon under study. Inclusion criteria for this study included women who: 1) were able to speak, read and write in English; 2) had no cognitive impairment; 3) have a diagnosis of IBC; 4) were adult women over the age of eighteen; 5) had completed multi-modality treatment regimens including surgery, systemic/biologic therapy and radiation within the last three years; and 6) reside in rural Manitoba outside the CMA of Winnipeg. Exclusion criteria included women who: 1) had

stage IV disease; 2) lived in the CMA of Winnipeg or surrounding municipalities; and 3) had relapsed or progressive illness.

Sample size for an interpretive description depends on the research question and nature of inquiry (Thorne, 2008). Considering the findings of the literature review and wisdom that is brought to this study, it is suggested that there are significant gaps in service and challenges that present rural women living with breast cancer in this province. Therefore, rich exploration of the underlying subjective experiential nature of the problem was required. Considering the research question, representation from all four rural Health Authorities provided a better understanding of the scope of this problem. The ability to compare and contrast the similarities and differences amongst the regions has benefitted this study as different challenges exist amongst regions. A sample size of n=5 participants in each region were recruited and captured the themes and patterns necessary to draw the conclusions required for this study.

Recruitment was achieved through a number of avenues. The nurse navigator at WCCH, rural navigators and oncology nurses or social workers in the rural CCP programs were the primary intermediaries that assisted with recruitment for the study. One woman approached the researcher independently through a poster that was posted on the WCCH bulletin board (Appendix F). All the recruitment sites were provided with recruitment information (Appendix G) and recruitment letter (Appendix H) that facilitated the recruitment activity. Additionally, telephone conversation between the intermediary recruitment nurses and primary researcher was also required to ensure purposive sampling of the participants was fulfilled. The intermediary site HCP approached potential participants and names were submitted to the primary researcher who initiated all contact with participants. Each potential participant received a personal phone call from the primary researcher and a telephone script

(Appendix I) was used to ensure a complete description of the study was provided. Willingness to participate was explored in these initial telephone discussions and informed consent was provided. Interview arrangements were made while ensuring a suitable time and place that met the needs of the women was considered. A total of twenty first interviews were conducted, eighteen interviews in a rural setting and two interviews in Winnipeg. All of the rural interviews occurred in the women's home with exception of two interviews. One interview occurred in a health care facility at the request of the participant and was arranged by the local social worker following consent. The second interview occurred in a private office at the woman's workplace. The interviews in Winnipeg took place in the setting that the women were living while relocated in city. Eleven second interviews were completed in a rural setting with one second interview completed in Winnipeg in similar suitable quiet settings. The final eight women were contacted a second time via mail or telephone correspondence but a second face-to-face interview was not completed. It was at this point the primary researcher in consultation with her advisor decided that data saturation had occurred and the final second interviews were not required. The data collection process resulted in over 10,000 kilometers of travel to each of the four RHA over a 1.5 year timeframe from June, 2015 to December, 2016.

Data Collection Methods

A demographic form, face-to-face interviews, journaling and field notes were methods utilized to collect the data for this study.

Demographic questionnaire. The first source of data collection was a demographic questionnaire (Appendix J). A simple, two-page form that took ten minutes for the participants to complete was provided to all the women. The form was used to track information such as

age, marital status, employment status and educational background, stage of diagnosis, ethnic background, and treatment details. As the interviews progressed or at the time second interviews, additional questions and timeframes were documented in the form of a second questionnaire that was initiated by the primary researcher (Appendix K). The demographic forms were analyzed by means of descriptive statistics and represented in Chapter 5.

Interviews. Face-to-face interviews were the primary source of data collection utilized for the study. The women took part in an open-ended, in-depth semi-structured interview which allowed the participant to tell their story in their own words and provided rich and thick descriptions of their individual experience. People like to share their stories and experiences so it is important that the researcher respects the spirit of this engagement (Thorne, 2008). Opening questions such as “Can you please tell me a little about yourself and family life before your diagnosis of breast cancer?” followed by “Can you tell me about the experience surrounding your initial diagnosis?” started the interview process. The interview then proceeded with questions about the cancer journey as it relates to the domains in the supportive care framework and challenges or benefits as it relates to living rurally. Probing questions were asked until the experience was thoroughly described. An interview guide (Appendix L) with open-ended and probing questions was developed to guide the process but each interview was unique to the participant and the probing questions were used to stimulate discussion. Semi-structured interviews of this nature allowed the women the liberty to respond to questions and probes and an open discussion occurred so they were able to narrate their personal experience as they wish. The women felt comfortable and were open to speak about their experience on their terms. The conversation was primarily led by the women and they shared their journey in a conversational-style interview. Mutual trust and respect between the researcher and the

participant was evident. The women were provided with details regarding the researchers nursing experience, student status, advisory team, and ethics consideration. Any questions that remained were answered prior to starting the interviews. If the woman had additional questions they were addressed following the interview or the tape was stopped at their request to address any concerns they had. Other interview strategies that were incorporated included active listening, expressions of interest and encouragement, moments of silence, re-phrasing, and calls for examples. The interviews lasted from 2 and up to 5 hours long. They occurred in a relaxed and quiet setting, were not rushed and comfortable for both the researcher and the participant. Each participant was encouraged to talk about anything they felt was relevant to the study and their unique experience.

Twelve second interviews were completed. The second interview afforded the opportunity to follow-up on questions arising from the first interviews and helped to confirm emerging findings. An additional purpose of the second interview was to ensure the researcher had adequate time with each participant to capture the true meaning of their experience. It provided the added time to become engaged in the personal story, make meaningful objective and subjective observations, verify the findings, and to ask further questions. A similar open-ended, semi-structured interview format was used for the second interview (Appendix M) in addition to specific questions for each individual interview that were crafted after careful review of the initial transcript. The participants who were interviewed a second time were given the choice to participate and in the setting of their choice. It is also important to note that the eight women who were not interviewed a second time were initially interviewed as a last series of interviews therefore accuracy of timelines and second interview questions were explored with these women. All the interviews were recorded to preserve authenticity and

transcribed verbatim. The primary researcher transcribed the first five interviews then contracted a qualified transcriptionist to complete the transcriptions for the remainder of the interviews. The transcriptionist signed a PHIA confidentiality agreement with the researcher and ethics approval and changes to the consent were approved in advance.

Reflective journaling and field notes. In qualitative research it is important to document what the researcher heard, saw, thought, and experienced. Observations, assumptions, personal narratives, and reflections were included as a part of the design. These notes became part of the data analysis and audit process as the study unfolded.

Data Analysis

Data collection and analysis is an iterative process (Streubert & Carpenter, 2011). Data analysis started as soon as data collection began. Inductive analytical techniques were utilized during data analysis that encouraged repeat immersion in the data during coding, classifying or creating linkages in the data (Thorne et al., 1997). The process of synthesizing, theorizing and recontextualizing was done during the sorting and coding process. This was required to provide the rich descriptions that are required in interpretive description (Thorne et al., 1997). Directed content analysis was the approach to data analysis that was utilized in this study.

A directed approach to content analysis was selected for this study. This method of content analysis is used to validate or extend conceptually a theoretical framework. An existing theory and prior research exists in this proposed study but further exploratory descriptions were required (Hsieh & Shannon, 2005; Zhang & Wildemuth, 2009). The existing framework provided direction to guide the research questions and aspects of the literature review. In the analysis process it provided predictions or relationships among the concepts of interest thus forming the basis to initial coding schemes and relationships between the codes

(Hsieh & Shannon, 2005). During the interview process both targeted, open-ended and probing questions were utilized considering the categories in the supportive care framework. Predetermined codes, concepts and categories were planned in advance of the interview process according to the domains, operational definitions, and concepts inherent in each domain (Hsieh & Shannon, 2005; Zhang & Wildemuth, 2009).

Eight steps guided content analysis (Zhang & Wildemuth, 2009). Step one involved preparing the data. All the digitally recorded data was transcribed into written text, verbatim. All the questions from the interviewer were transcribed as well. Other subjective data and observations, such as reflective notes of the researcher or field notes were also captured. In step two, the unit of analysis was defined based on the concepts embedded in the supportive care framework. The concepts were developed from the operational definitions and concepts identified under each domain. Concepts were analyzed in the initial text and expressed in a word, phrase, sentence, paragraph, or an entire passage noted in the text (Zhang & Wildemuth, 2009). Step three, involved categorizing the data based on the domains in the supportive care framework. As new categories emerge inductively through the data collection and analysis process these coding schemes were expanded on or modified. In step four, validation of the coding scheme was required. This must occur early on in the process of data collection. A coded sample was analyzed according to the operational definition under each domain. If there is doubt or concern about the category definition, then discussion between the primary researcher and advisor occurred and modifications were made. This process of checking coding consistency is an iterative process and the process of coding sample text, checking coding consistency and revising coding rules continued until consistency was achieved (Zhang & Wildemuth, 2009). Once coding rules were established, step five involved coding all the raw

data. As new data was collected new concepts emerged and were added to the coded material. In step six, the data was collected, coding consistency was repeated. The entire text was reviewed multiple times to ensure coding categories remained consistent. In step seven, patterns and meanings were derived from the data. The final step involved reporting the findings (Zhang & Wildemuth, 2009). The findings have been presented in Chapter six and categorized according to the domains in the framework.

Collaborative analysis with my thesis advisor occurred at each step in the data collection and analysis phase of this research process. The advisor has provided the student with guidance and expertise in directed content and constant comparative analysis. Collaborative analysis ensured an accurate description of what the participants shared was reported.

Methodological Rigour and Trustworthiness

Considering issues surrounding methodological rigor and credibility in any qualitative work is important. Operational techniques were required throughout the research process to ensure a trustworthy study was produced and subsequently reported in the findings (Streubert & Carpenter, 2011). Four criteria were utilized for evaluating this qualitative research work which included credibility, dependability, confirmability, and transferability (Streubert & Carpenter, 2011; Zhang & Wildemuth, 2009). Each of these principles will be outlined and strategies illustrated.

Credibility

In all qualitative research studies it is important that credible findings are produced and presented in the dissemination process (Streubert & Carpenter, 2011). Credibility is directly related to how well data collection and analysis processes were developed and implemented.

Strategies need to be implemented to ensure that credibility is maintained. The strategies that were included in this research design included prolonged engagement in the field, persistent observation, member checking, triangulation of data sources, negative case analysis, checking interpretations against raw data, developing transparent well-defined coding procedures and peer debriefing (Streubert & Carpenter, 2011; Zhang & Wildemuth, 2009). The researcher had adequate time with each participant to capture the true meaning of their experiences which allowed time to become engaged in the personal story, make meaningful objective and subjective observations. Twelve second interviews were completed to further validate the findings and further questions were presented. Multiple data sources such as the demographic form, repeated interviews, note-taking, and journaling allowed the researcher to analyze the data from different perspectives. Taping the interview preserved the authenticity of the interview and was played back as required if meanings need to be re-interpreted. Transparency of these measures adds credibility to the overall findings. Checking and re-checking data and coding categories, creating alternative questions, comparing data sources, seeking answers to unanswered questions were strategies utilized to ensure a credible product was produced. Mentorship from the primary advisor at each stage of the process was maintained. She reviewed the analyzed data to validate the interpretation of the primary researcher and ensure a credible product.

Dependability

Dependability follows credibility. If the results are not credible they will not be dependable and is directly related to the internal process described in the previous section. Illustrating a credible product, triangulation of methods and ensuring the researcher accounts

for changing conditions in phenomena add to the dependability of the results (Streubert & Carpenter, 2011; Zhang & Wildemuth, 2009).

Confirmability

To ensure confirmability, the researcher must illustrate as clearly as possible the evidence and thought process that led to the conclusions of the study (Streubert & Carpenter, 2011). Leaving an audit trail, or recordings over time, is a strategy used in qualitative research to ensure that confirmation of the study can be substantiated. Clear documentation of internal data including raw data, field notes, memos, coding manuals, and journals to ensure the integrity and internal coherence of the research project is maintained. Member checking and peer debriefing are all strategies to ensure confirmability and approaches that were used in this study (Zhang & Wildemuth, 2009).

Transferability

Transferability of study findings from one setting to another adds to the trustworthiness of the study findings. Transferability can also be labeled as “fittingness” and the potential users of the findings can only answer this question. It is the responsibility of the producers of the research to provide descriptions that are rich enough so that other researchers or HCP can make judgments about the findings’ transferability to different situations. Justification of sample size and outlining the limitations of the study are techniques used to enhance transferability of a study (Streubert & Carpenter, 2011; Zhang & Wildemuth, 2009).

In an interpretive descriptive product the credibility of the findings will be derived largely in the presentation of the analytic decisions and contextualized within the larger picture (Thorne et al., 2004). An additional criterion to ensure a trustworthy study as described by Thorne (2008) is epistemological integrity which is further described.

Epistemological Integrity

All qualitative research is expected to demonstrate epistemological integrity. The underlying theoretical assumptions of the study have been outlined. The research question is consistent with the epistemological assumptions of this study as human illness experience and shared realities were explored. The decisional strategies that were made respect the underlying assumptions presented in the earlier section (Thorne, 2008). This study is rooted in the interpretive naturalistic orientation. The study participants were interviewed in a naturalistic setting of their choosing. Comfort and ethical rights of the participants were considered at all times. The participant's subjective and experiential knowledge of their breast cancer experience formed the basis for the study findings. Both common and individual experiences were analyzed during the analysis process. The relationship developed between the researcher and participant was one of respect and trust. Relationship building, exploration of experiences, and joint participation are important aspects of the interview process. Allowing appropriate time for the participant to share their personal story, acknowledge their feeling, while providing empathy and support was upheld. Reflexivity, during the journaling process was done with each interview as multiple realities can exist which could contradict what is known. Awareness that this was possible was upheld and objectivity maintained. All of these strategies helped maintained the epistemological integrity of this study (Thorne, 2008).

Ethical Considerations

Nurse researchers have the responsibility to design research based on sound ethical principles and protection of human rights (Streubert & Carpenter, 2011). Ethical issues related to regulatory requirements, informed consent, participant-researcher relationships, coercion, gaining access, confidentiality, anonymity, data protection, and publication need to be

acknowledged and require special attention. Regulatory requirements are outlined in the following section. This is followed by a description of the core ethical principles of autonomy, non-maleficence, beneficence, justice, and confidentiality in the context of research (Keatings & Smith, 2000; CNA, 2008). Lastly, risks and benefits to the participants will be outlined.

Regulatory requirements

Ethics approvals were obtained from Nursing Research Ethics Board (NREB) at the University of Manitoba (University of Manitoba, 2014) and all the four rural RHA. Approval was also required from the Research Resource Impact Committee (RRIC) located at CCMB (CCMB, 2014b) and the medical director of the breast disease group at CCMB (Appendix N). Considering the need for multiple approvals, extensive recruitment strategy, multiple interviews and extensive travel to all regions of the province, an extended NREB approval was also necessary and is currently in place until March, 2019. In addition to being a novice researcher, I am also a registered nurse who conducts client interactions according to the Canadian Nurses Association, Code of Ethics for Registered Nurses (CNA, 2008). I have also been trained and signed a Privacy Health Information Agreement (PHIA) with each of the RHA and CCMB and completed the required ethics tutorials mandated by the University of Manitoba.

Autonomy

To uphold the principle of autonomy it is essential for individuals to have the desired information in advance so make an informed decision on which to participate in the study (CNA, 2008; Streubert & Carpenter, 2011). An informed consent (Appendix O) was obtained from all participants prior to entering the data collection process. The consent provided them with all the relevant and adequate information they needed prior to entering into the study. In

qualitative research, process informed consent is also required which ensures that the participant is informed throughout the process (Streubert & Carpenter, 2011). As question or concerns arise during the interview process the researcher ensured informed consent and autonomy is upheld. The participants signed the consent at the beginning of the study and were made aware that they could withdraw from the study at any time as their participation was completely voluntary. If a second interview or telephone conversation was required they were told that they had the right to decline. However, this did not occur and all the women who were interviewed a second time happily agreed to participate. Further strategies to uphold the principle of autonomy included:

1. No dual relationships were present within the study.
2. Participants were notified of the study in the form of a letter or personal conversation by a person who was not affiliated with the study to prevent any feelings of coercion to participate. The researcher did not have access to any names or personal information until permission was granted by the participant to be contacted.
3. All participants were of legal age and willingly volunteered to be interviewed.
4. Participants had the right to withdraw at any time. They also were able to choose not to answer any question or stop the interview at any time.
5. Interviews occurred at a time and location of the participants choosing. Timing and length of interview was discussed with the participant in advance.
6. Prior to consent, written description of the study purpose, methods of data collection, and time commitments were discussed. My student status, thesis supervisor's name and credentials, and university affiliation was also described. Contact numbers of primary researcher, advisor and the Human Ethics Secretariat was provided. Additionally, all

information was verbally presented, in person and time was allowed for questions. Risk and benefits of the study was outlined prior to attaining consent.

Non-maleficence

The principle of non-maleficence obliges us to prevent or remove harm (Keating & Smith, 2000). Throughout the research process it was important to be aware that this research topic can elicit feelings from past and present experiences that may be difficult and evoke unpleasant memories or experiences. Sensitive issues may arise by asking probing questions to elicit the necessary data under study. Potential risks to the individual are psychological in nature and participants were made aware that they can waive their right to participate at any time or refuse to answer any questions. This risk was explained to the participants in advance of the study.

When conducting a qualitative interview, there is always a possibility that potential adverse reactions can occur when eliciting past memories. When entering research with vulnerable populations based on a difficult topic, stress and unwanted emotions can occur. Empathy, support, and objectivity of the researcher were required. If this potential problem were to arise, the plan for intervention included: audiotape would be stopped and validation of feelings and support would occur; if the participant is able compose themselves the interview would continue; if the participant is unable to continue, measures would be taken to ensure they have the appropriate resources available to them for ongoing support; appropriate support and empathy would be provided at the time by the researcher until the participant can compose themselves; therapeutic communication techniques and validation of feelings would be implemented; and exploration of access to additional supportive networks would be offered. It must be assured that the person has appropriate access to the support they need. Psychosocial

oncology practitioners are located in seven rural areas across the province. Provisions to use these supportive care services were arranged in advance of the study. During data collection if these services were required appropriate contact information would be provided. Permission would be granted for this researcher to contact someone on behalf of the participant. As well, the participant would be provided with the primary researcher and thesis advisor contact information in the event they wish to contact us following the conclusion of the interview. During the time of the interviews there were women who became emotionally upset by the discussion. There were times when the interview was stopped and tape was turned off. In each of these situations, the women were able to compose themselves with the support of the researcher and re-enter into the interview process. All the women were provided with a contact at CCMB in psychosocial oncology and told that they were free to initiate contact if they were in need of further assistance.

Beneficence

Beneficence is linked to non-maleficence but one must take a higher standard to produce some good or benefit for another (Keating & Smith, 2000). Every effort was made to ensure participants were well informed and making an autonomous decision to participate in the study in keeping with this principle. Beneficence is also achieved by being sensitive to the emotional responses of the participants. Any undue stress or emotional distress was dealt with in a supportive and therapeutic manner. Additionally, maintaining confidentiality falls under the principle of beneficence which will be discussed in the following section (Streubert & Carpenter, 2011). All the participants were also informed that they will receive a summary of the study's findings and the appropriate clinical recommendations that are suggested.

Justice

The ethical principle of justice is to treat people with equity and fairness in a way that is morally right and proper (CNA, 2008; Streubert & Carpenter, 2011). Distributive justice considers that each person is considered equal, are not discriminated against while considering fairness and inclusiveness (CNA, 2008). The voice of all rural women with breast cancer should be measured while considering the scope of the problem in rural areas. All women who expressed willingness to participate were approached and included in the study. It is also important to ensure that people who decline to participate are treated with respect, dignity, and with a non-judgmental approach. This was not the case in this research study as all the women willingly participated in the study. In addition, the researcher will not discriminate or was sensitive to issues surrounding race, ethnicity, culture, spiritual beliefs, social or marital status, sexual orientation, lifestyle, or mental or physical disability (CNA, 2008). In this study, many sensitive issues arose and added a richness and complexity of the experience which will be described in the findings chapter.

Confidentiality

All participant issues surrounding privacy, confidentiality, and anonymity were discussed during the consent process. A promise of confidentiality is a pledge to the participant that personal information will not be made accessible in any way (Streubert & Carpenter, 2011). In qualitative design, the nature of data collection makes anonymity impossible. Small sample sizes and detailed interviews by their very nature breach anonymity. It is essential in this research and the responsibility of the researcher to make all efforts to ensure confidentiality is maintained. No names were attached to any of the data collection materials. Code numbers were used on all the data material. All materials including consent forms, digital taped data, files, and coded field notes are kept in a locked cabinet in the researcher's home.

Consents and list of contacts will be kept separate from this data. All data will be shredded and deleted from computer files and digitally taped data will be erased in five years after the study is completed.

The primary researcher and thesis advisor were the only people with access to the audiotape and raw data. The PHIA bound transcriptionist also had access to the tape but all efforts were made by the researcher to ensure safe exchange of data was upheld. All participants were assigned a pseudonym and any identifying information was altered to ensure confidentiality. Finally, the participants were informed how the research will be disseminated and were made aware that identifying and demographic data will not be revealed anyway.

During the consent process the participants were informed that the researchers is bound by the Protection of Persons in Care Act, therefore any abuse, physical, emotional, sexual or financial in nature, is the responsibility of the researcher to disclose. This process was not required in this study.

Risks and Benefits to Participants

As previously outlined, the potential risks to the individual are psychological in nature and they were made aware that they can waive their rights to contribute at any time. There is a therapeutic benefit to sharing experience. To be able to share thoughts, feelings, and concerns provides an avenue to express emotional and psychological responses associated with the rural cancer experience (Fitch, 2008; Langhorne et al., 2006). There is also a benefit to knowing that this particular research study has the possibility to create positive change for future breast cancer patients and can be empowering for those involved. All the women felt that the research was very valuable and felt thankful to be involved. Additionally, many of the women described the therapeutic benefit to participating and being able to tell their story in such an

open-ended, supportive and non-judgmental way. No tangible benefits or financial compensations for the participants were provided. Each participant will be provided with a detailed description of the study results and associative publications at their request.

Chapter Summary

In this chapter, an interpretive descriptive qualitative study is presented. Philosophical underpinnings guiding the research study are outlined. Data was gathered through in-depth, semi-structured interviews, demographic profiles and field notes. Rural women with IBC from all rural regions of the province were included in the sample. Data analysis strategy was achieved through directed content analysis. Methodological rigour and trustworthiness has been outlined. Regulatory requirements have been outlined and consideration has been given to the core ethical principles of autonomy, non-maleficence, beneficence, justice, and confidentiality. Lastly, risks and benefits to the participant are outlined. In the following chapter, a presentation of the demographic findings will be presented.

Chapter 5: Demographic Findings

This chapter presents a description of the women who participated in the study as well as the treatment modality demographics. Regional and travel demographics will also be outlined. The demographic findings in this study were collected through the demographic and timeline forms located in the Appendices. Additional demographic data was captured through the interview process and included in the descriptions.

Participant Sample

Sample Description

Twenty women were recruited to the study utilizing multiple intermediary sites from four RHA. Age, marital status, living in residence, employment status and history, educational and ethnic background data is located in Table 5.1. The widowed women were 64 years of age or older. The single and married women represented four of the age categories and the separated women represented two age categories. All of the women who lived alone were either single or widowed. One single woman lived with her adult daughter and two separated women lived with adult children and a grandchild. The children living with four different women were all under the age of 10 years and were either their primary children or grandchildren. Two women lived in an apartment in their home community and twelve women lived in a home in a city or town. Six women lived in a home on a farm or large acreage in close proximity to a town or city. The 10 employed women worked in a variety of settings such as home-based businesses, health care, child care, retail or office positions and 5 women were able to maintain their employment at some capacity. Nine women were retired and one woman was a homemaker. All the women were able to complete the demographic form and answer the questions to the best of their ability. All the women spoke English fluently.

Table 1: Breast Cancer Participants: Sample Description

Characteristic	Number (%)
<u>Age</u>	
Age Range	34-84 years
Mean Age	58.1 years
34-45 years	2 (10%)
46-55 years	6 (30%)
56-65 years	8 (40%)
66-75 years	2 (10%)
76-85 years	2 (10%)
<u>Marital Status</u>	
Married	11 (55%)
Single	4 (20%)
Widowed	3 (15%)
Separated	2 (10%)
<u>Living in Residence</u>	
Alone	6 (30%)
2 Adults	10 (50%)
2 Adults and Children	2 (10%)
More than 2 Adults/Children	2 (10%)
<u>Employment Status</u>	
Employed	10 (50%)
Retired	9 (45%)
No employment	1 (5%)
<u>Worked through Treatment</u>	
Yes	5 (50%)
No	5 (50%)
<u>Highest Level of Education</u>	
Below Grade 12	3 (15%)
Grade 12	7 (35%)
Post secondary	10 (50%)
<u>Ethnic Background</u>	
Caucasian	17 (85%)
Métis	2 (10%)
Aboriginal	1 (5%)

Treatment Modality and Breast Cancer Demographics

All the women were diagnosed with IBC from September 2012-December 2015. Twelve women were diagnosed at stage two at time of diagnosis and three women were diagnosed at stage three. Five women were unsure of the stage of their cancer. However, based on the treatment all women met the criteria for the study requiring multi-modality regimens including surgery, chemotherapy +/- biologic therapy and radiotherapy. Additionally, seventeen women required long-term hormone therapy as part of the treatment plan. The women had a wide range of surgical interventions. One woman opted to have a unilateral mastectomy and implant verses tissue reconstruction as a surgical option. The other women who choose reconstruction as an option proceeded with tissue reconstruction including the graphing procedure. One woman had completed multiple post-reconstruction cosmetic surgeries and the other women were still in the decision-making process on whether to proceed. All of the women received four and up to eight cycles of multi-agent adjuvant chemotherapy and 35% required biologic therapy for an additional year. Three women in the high risk category had their chemotherapy prior to their surgical intervention. At the time of the interviews three of the women were still completing their Hercepten therapy. All of the women required involved-field radiotherapy as a part of their treatment regimen and commuted to either Winnipeg or Brandon to receive this therapy. Eighteen of the women had completed their radiotherapy and two women were nearing the end of their therapy at the time of the interviews. Sixteen women had initiated hormone therapy and will remain on this treatment for an addition 5-10 years. Many different hormone treatments were initiated including Letrazole, Tamoxifen, Zolodex, Extemestane and Eligard. Some women were required to switch therapies due to intolerance. All of the women were within three years following completion of their radiotherapy at the time of the interviews. Table 5.2 illustrates the

treatment modality demographics including surgery, chemotherapy/biologic therapy, radiotherapy, and hormone therapy.

Table 2: Treatment Modality Demographics

Demographic	Number
<u>Surgical Intervention</u>	
Bilateral Mastectomy and Reconstruction	3 (15%)
Unilateral Mastectomy and Reconstruction	2 (10%)
Bilateral Mastectomy/No reconstruction	3 (15%)
Lumpectomy	10 (50%)
Unilateral Mastectomy	1 (5%)
Unilateral Mastectomy and Implant	1 (5%)
<u>Chemotherapy</u>	
Chemotherapy alone	13 (65%)
Chemotherapy plus Hercepten	7 (35%)
<u>Low Risk</u>	
Docetaxel/Cyclophosphamide (TC)	1 (5%)
TC + Hercepten	2 (10%)
<u>Intermediate Risk</u>	
Fluorouracil/Epirubicin/Cyclophosphamide/Docetaxel(FEC-D)	10 (50%)
FEC-D + Hercepten	4 (20%)
<u>High Risk</u>	
Neoadjuvant FEC-D	2 (10%)
Neoadjuvant FEC-D + Hercepten	1 (5%)
<u>Radiation Therapy</u>	
Involved Field Radiation therapy	20 (100%)
<u>Hormone Therapy</u>	
Yes	17 (85%)
No	3 (15%)

Regional and Travel Demographics

All the women were interviewed in the setting of their choice which mostly included travel to their home communities. Fourteen women lived in the rural town or city while six women lived outside of the adjacent town or city in a farm-like setting but had close access to the amenities in the local community. Five participants from PMH had access to additional services at Western Manitoba Cancer Center (WMCC) located in Brandon, MB including radiation and surgical oncology. However, not all the women accessed all of the services. Two women from SHSS had access to Boundary Trails Health Center which provides additional diagnostic services. The majority of women travelled to treatment by land however four women from the NH utilized air travel for some of their travel requirements. All the women had to commute for the surgical procedure to either Winnipeg or Brandon with the exception of one woman who lived very close to Brandon. All the women had an escort accompany or drive them for their surgery. Four women did not have a local CCP in their home community. Three women travelled 42, 52 and 178 kilometers (km) one way for each of their chemotherapy treatments and would return home the same day. All of these women had an escort or driver service accompany them. The woman who travelled 178 km opted to move to a different site and travelled 157 km one way for the remainder of her Herceptin therapy. In this situation, she drove herself. The fourth woman was from a remote northern community and travelled by air but mostly remained in Winnipeg for the duration of her chemotherapy. Sixteen women had their radiotherapy in Winnipeg and four women had their treatment in Brandon. Eleven women relocated to the center that provided their radiotherapy treatment. Seven of those women were alone for the time that they were required to relocate. The women stayed in various accommodations including supportive housing, hotels or with family or friends. Nine women opted to commute daily for

their radiotherapy treatment and seven women had a support person or escort to drive them to their appointments while two women drove independently. Table 5.3 outlines additional regional and travel demographics.

Table 3: Regional and Travel Demographics

Demographic	Number
<u>RHA</u>	
Interlake Eastern Health Authority	5 (25%)
Prairie Mountain Health	5 (25%)
Southern Health Sante Sud	5 (25%)
Northern Health	5 (25%)
<u>Municipal Population</u>	
City (Greater than 7,500)	11 (55%)
Town (Less than 7,500)	9 (45%)
<u>Rural Community Cancer Program</u>	
<u>Located in Home Community</u>	
No	4 (20%)
Yes	16 (80%)
<u>Travel Distance to Winnipeg (All participants)</u>	
Distance Range	62-1100 km
Mean Distance	329.25 km
Under 100 km	5 (25%)
100-300 km	6 (30%)
301-500 km	4 (20%)
Over 500 km	4 (20%)
Over 1000 km	1 (5%)
<u>Travel Distance to Brandon (Five participants)</u>	
Distance Range	15-182 km
Mean Distance	121 km
Under 100 km	2 (40%)
Over 100 km	3 (60%)
<u>Mode of Travel</u>	

Air	2 (10%)
Both Air and Land	2 (10%)
Land	16 (80%)
<u>Surgery Location</u>	
Winnipeg	17 (85%)
Brandon	3 (15%)
<u>Chemotherapy Location</u>	
Winnipeg	2 (10%)
Rural Community Cancer Program	18 (90%)
<u>Radiation Location</u>	
Winnipeg	16 (80%)
Brandon	4 (20%)

Chapter Summary

This chapter provided an overview of the participant and treatment demographics of the women who participated in the study. Also, the regional and travel demographics were also highlighted. In the following chapter, the qualitative supportive care findings will be featured. The findings have been categorized according to the seven domains in the supportive care framework.

Chapter Six: Supportive Care Findings

The findings for this study have been categorized according to the seven domains in supportive care framework (Fitch, 2009). Physical, informational, social, practical, emotional, psychological, and spiritual domains of the women have been explored, analyzed, compiled and summarized in this chapter. Each domain emphasizes the distinct challenges and positive aspects associated with living in a rural area of the province and include comparisons of services and challenges from a regional perspective. Other unique variables based on the age, marital status, family situation, geographic location, or employment status has also been featured. Finally, recommendations that the women suggested for service improvement or support required to enhance the care for rural people living with cancer are featured throughout this chapter.

Physical Domain

The operational definition of this domain, defined by Fitch and colleagues, states that Physical needs are based on “physical comfort and freedom from pain, optimum nutrition and ability to carry out one’s usual day-to-day functions” (Fitch, 2009 pg. 18). The physical domain description has been featured based on four broad categories including symptom of illness and diagnosis, side effects of treatment, psychomotor care processes and management of emergencies and other health care services. The following table illustrates the heading summary in the physical domain.

Table 1: Physical Domain Summary

1.1 Symptom of Illness and Diagnosis
1.2 Side-Effect of Treatment
<ul style="list-style-type: none"> • 1.21 Surgery • 1.22 Chemotherapy/Biologic Therapy • 1.23 Radiotherapy • 1.24 Hormone Therapy

1.3 Psychomotor Care Processes
1.4 Managing Emergencies and Other Health Care Services
1.5 Domain Summary

1.1 Symptoms of Illness and Diagnosis

Initial presentation of illness varied among the women. Four of the women reported that they did not experience any physical symptoms at initial presentation. The first sign of a problem was detected on screening mammography. Nine women detected an initial lump through self-examination and subsequently entered into the diagnostic phase of illness. One woman described a four week wait from detection of the lump to biopsy. In this situation, she did not have a family doctor because of the frequent transitions of doctors in the community. Four women experienced more advanced findings to the breast such as nipple inversion, puckering or chest wall changes. One woman described a change in her breast but did not seek treatment for many years because of her aversion to seeking medical care. Additionally, four women reported that they delayed seeking investigation for other reasons. The youngest women who participated in the study did not even consider a breast cancer diagnosis based on her age. She had changes to her breast wall for months which she attributed to a muscle injury.

I still had this like growing mass ... 'cause at this time my mom hadn't been diagnosed with breast cancer and I wouldn't even think to consider that it would have been something just 'cause of my age 'cause at that time I would have been like 28/29 and so I wouldn't even consider this to be anything except for a pulled muscle. (A2, lines 155-160)

Other reasons for delay of investigation were based on challenges with the travelling mammogram system that is set up in the province. One woman described a very difficult and painful experience she had with the travelling mammogram program which resulted in a delay in seeking screening mammograms based on her fear of having another painful procedure. She

subsequently found a large lump and received a diagnostic mammogram at her community hospital and compared it to her travelling mammogram experience *she did the whole thing and she did not cause me any pain at all (D3, line 264)*. She later described concern that her cancer was diagnosed at a later stage because of her fear of seeking mammography through her rural travelling program. Another woman talked about her inability to access traveling mammogram because of her age. She missed her yearly mammogram because she was unable to travel to Winnipeg due to weather conditions. Although, she was not experiencing physical symptoms of illness, she was still concerned with the lack of service in her rural community but continued to have challenges accessing service in Winnipeg based on her age.

I missed that horrible winter of 2013/14 because I was snowed in most of the winter... so I was late getting my mammogram. I'm too old to have them from this travelling clinic ... We only do up to 74 but because you came so far we'll do it as a matter of courtesy. (C2, lines 15-16, 26-29)

The lump was found on this initial mammogram and she was referred to a surgeon immediately for a biopsy. She voiced frustration over the process stating *it's like a mammogram that they don't want to give you when you're past 74, I think that's age discrimination (C2, lines 487-488)*.

Three other women were diagnosed inadvertently based on other unrelated symptoms which eventually resolved and the breast cancer diagnosis became their focus.

During the diagnostic phase of illness, the women were required to travel frequently to Winnipeg or Brandon for multiple tests and consultations with physicians. From a physical perspective, procedural pain was the mostly frequently reported finding in this stage of illness while other physical concerns did not come out in any of the interviews. The biopsy was described as the most uncomfortable procedure.

You know, don't move, sorry it hurts, it did, I felt like I was literally blacking out 'cause it hurt so bad. (A1, lines 537-538)

Many of the women reported receiving very efficient and fast diagnostic services at first suspicion of illness and only two women reported time from diagnosis to start of treatment greater than 60 days and felt that improving wait times would be an important recommendation moving forward. No other physical symptoms were described in this phase of illness.

1. 2 Side-Effects of Treatment

The women experienced a wide range of side-effects during the course of their cancer journey. Some of the side-effects were temporary and some have become a more permanent affliction for the women affected. Side-effects also varied depending on the treatment modality they were receiving. It was apparent there were challenges with each modality of treatment but as the interviews unfolded chemotherapy-induced toxicity proved to be the most toxic and resulted in more challenging immediate side-effects. Each treatment modality will be described in this discussion.

1. 21 Surgery. Ten women received a lumpectomy as their primary surgical intervention. Most of the women reported that they were in and out of hospital overnight or on the same day of surgery. Predominantly, the post-operative experience was uneventful with minimal physical impact on the women. A quick recovery period was often described. However, the most common physical symptom that was identified post lumpectomy was post-surgical pain and discomfort. This side-effect was well managed and did not become the focus of the described experience. Some of the women reported a physical change to the breast but this became secondary to having the cancer removed. Two women reported post-operative complications following their lumpectomy which made the journey more challenging. One woman described developing an

abscess when she returned to her home community. She subsequently required an additional surgery to drain the abscess and home care support. In this situation, she was able to obtain the care she needed in her home community. Another woman described a life threatening post-surgical complication resulting in a second operative procedure and delayed her discharge from hospital for many days.

My surgeon decided to keep me because my blood pressure had dropped and then two hours post-op I had an arterial bleed and yeah, yeah that was very scary. (B5, lines 345-347)

Two women required a unilateral mastectomy and three women received a bilateral mastectomy as their primary surgical intervention. These women decided against having reconstruction for individual reasons. The side effects that were described post-mastectomy included lymphedema, arm numbness, weakness, post-surgical pain, sleep disturbances, and a post-surgical abscess. One woman described suboptimal surgical care at a Winnipeg hospital including inadequate pain control which resulted in her leaving hospital early and a painful drive home to her rural community. This woman felt it was important for HCP to consider post-surgical pain control measures are in place for rural people required to travel long distances considering early discharge from hospital when the pain experience is heightened.

I said to my husband, we are going home right now because I'm in so much pain I cannot even imagine getting out of the vehicle...I said I just want to go home, I want my own bed which was not the wisest choice considering my surgery was, I was discharged less than 12 hours after my surgery was done (B3, lines 977-981)

Other women described travel exacerbating post-surgical pain but this was mostly relieved by splinting with pillows or avoiding the use of a seat belt. Six women opted for a unilateral or bilateral mastectomy including breast reconstruction as their primary surgical intervention. It was reported by all women that recovery time and hospital stay post-surgery was increased based

on the complexity of the reconstruction surgery and grafting procedure. Similar physical descriptions were reported post-surgery with these surgical interventions including pain, fatigue and weakness. However, it did become apparent that the lengthy surgical intervention and hospital experience made this surgery more difficult. In addition to a lengthy and complicated surgery, the women also had the additional tightness and discomfort associated with skin flaps to contend with. Women also reported that they may require additional cosmetic surgeries post therapy including repair of surgical flaps, breast re-shaping and nipple tattooing or reconstruction. One woman reported having 6 surgeries to date and described the physical limitations and decrease strength associated with multiple surgeries to be problematic. This woman described how she would have benefited from physiotherapy support at the beginning of her journey.

And just 'cause I have no strength anymore 'cause I'm recovering all the time, so you don't want to use anything, so you're, like I have no core strength, I have nothing and I used to be relatively active and took care of myself. (A2-2, lines 113-116)

The other women are still in the consultation and decision-making process on whether to proceed with these surgical and cosmetic interventions. Therefore, the physical demand of multiple reconstructive or cosmetic procedures was not captured in any of the other interviews but the decisional conflict associated with proceeding was often discussed. Overall, many women described a relief to have the cancer removed and the following treatment modalities proved to be more physically demanding.

1. 22 Chemotherapy and biologic therapy. The next line of therapy the women received was chemotherapy followed by biologic therapy if indicated. Some of the women received chemotherapy prior to their surgical intervention but the side-effects remained

consistent. There were many common side-effects experienced by all the women but there were also less frequently reported side-effects that were unique to the individual experiences.

Alopecia was experienced by all the women and was mostly accepted as inevitable. The impact of losing hair affected women in many different ways. Some women felt that it was the most difficult part of their journey, while others happily wore scarves and hats and realized that it was temporary. One woman described her journey with being bald as an opportunity and felt it did not define her as a person. Whereas, other women described the hair loss as a very difficult part of their overall journey causing significant body image challenges.

The losing of my hair was very, I hated that, I, I would not look at myself in a mirror unless I had one of those caps on. I, I just, I, that, and I, you know I lost my eyebrows and everything, it was, that was the worst for me. I mean I, I would have rather been sick three extra days than lose my hair, but there was no options there, it was going to happen and it did. (C5, lines 1214-1218)

Hair loss was also experienced in multiple sites including the head, eyelashes, eyebrows, arm and leg hair, pubic and underarm hair. This was often described as an unexpected or more difficult side-effect than losing hair on the head. Additionally, two women reported that now many years following completion of their therapy their hair re-growth is either sparse or non-existent. One woman who is three years post completion of her chemotherapy described her hair loss as a constant reminder for her of her cancer diagnosis.

I have no hair...And it's kind of tough when you look in the mirror, you want to get past it 'cause if you have hair you're not a cancer victim anymore. (B2-2, lines 41-44)

A number of women talked about how they would have benefited from additional resources or programs to help them managed alopecia as there are limited resources in their rural settings.

Fatigue was the second most frequently reported side-effect of chemotherapy. Fatigue significantly affected quality of life and functional capacity of the women who were affected. One woman had a number of mobility issues related to other medical conditions. Compounding chemotherapy-related fatigue led to a significant decrease in her functional capacity resulting in the need for daily home care support. She described herself as a highly active person and spent six months immobile and unable to function around the house.

And I was just exhausted...trying to go, just walking upstairs from the bedroom to the bathroom, it was like you know and I couldn't, and this lasted for a long time. (C3, lines 533-535)

Another woman talked about how taking a walk was a daily ritual she and her husband shared. During her chemotherapy treatments she was so weak and fatigued that she was unable to enjoy this simple. Additionally, fatigue was the most commonly reported progressive and escalating side-effect to Herceptin therapy. One woman who lived alone decided to seek alternative therapy from a naturopathic specialist to help her manage her progressive and debilitating fatigue which significantly affected her daily living. Another woman was told by her HCP that her level of energy may never return following Herceptin therapy. In this situation, the woman runs a busy home-based company and is uncertain she will be able to return to work in the same capacity.

I'm still very very exhausted. Two weeks ago I was so exhausted that I was sick to my stomach...I don't like the fact that my life is not predictable, that I could be going along thinking, oh look I'm getting more and more energy...no idea whether two weeks from now will be when I crash, because right now my energy is sort of a rollercoaster pattern. (D3, lines 869-872)

Fatigue markedly affected the woman ability to be independent. Driving, housework, or work demands became tasks that they could no longer take for granted. A number of women who lived

alone felt managing daily tasks were challenging related to ongoing fatigue and services such as meal preparation or housekeeping would have been of benefit.

Neutropenia was the third most frequently reported side-effect of therapy resulting in a variety of different infections. Febrile neutropenia, pneumonia, vaginal infections, cellulitis, thrush, and foot infections were some of the notable problems that the women endured. One woman experienced repeated infections which resulted in her feeling very ill through many of her treatments.

Ten days later again and I've got like five blankets on top of me and got a fever again, but I thought it happened the same time as the other times, probably chemo related...it happened every time, every time, every, three times with the fever" (B4, lines 848-853)

Neutropenia significantly affected the women in many ways including feelings of isolation in the social domain. It also caused other challenges such as the need for Neupogen injections and frequent visits to the emergency.

Side-effects were also reported that affected the women's ability to maintain their nutritional status. These included nausea and vomiting, mucositis, food aversions, taste changes, diarrhea, constipation, heartburn, anorexia, and bleeding gums. The women also described side-effects that affected their mobility including body tremors, dizziness, palpitations, anemia, leg swelling, and palmar plantar syndrome. Joint pain was another side-effect that frequently occurred.

Every bone in my body hurt, my mouth hurt, and I was alone with the two boys... I couldn't even barely move and I just curled up on the couch and they just sat beside me, trying not to touch me. But I mean when they told me that, about the chemo there was going to be some joint pain...you didn't tell me it was going to hurt like that. (A4, lines 432-439)

A side-effect that was described by many women affected their memory and was often referred to as “chemo or brain fog” which appeared to be a long-term, ongoing problem that was not resolving post therapy. Many described it would affect their ability to work or function with simple day-to-day activities such as shopping or driving. One woman has lived in her rural town for her entire life and knew almost everyone in her home community and described her experience when she returned to work.

It's like almost like a fog or something. Things that you used to remember you don't remember....Like when I went back to work... people would come in...I'm looking at them and I know who they are and I can't say their name... and it's strange.... because I've known them my whole life (B1, lines 1698-1708)

It also became apparent that not all side-effects were experienced by all the women and would affect them differently. Although there were many common side effects described by the women, the severity and ability to cope with the symptoms also varied. Additionally, it was also mentioned by a number of women that when they were just starting to recover from a chemotherapy treatment, then the next treatment would begin and the symptoms would start all over again. One woman had an extremely difficult time during her chemotherapy treatments requiring changes to the doses of her drugs. In both interviews, she talked about the physical challenges with each chemotherapy treatment that markedly affected her quality of life.

What it was is like there were times I, I prayed not to get up in the morning, I didn't want to live through the night. I remember being really sick...And then I just kept thinking okay, I know I will get better, but as soon as you get better you're zapped again. (B2, lines 974-978)

Many of the women stated that it would have been very difficult to travel based on their physical symptoms and felt fortunate to have a CCP nearby. The positive impact of the rural CCP was described frequently throughout the interviews. Although, in three situations some land

and air travel was required. One woman commuted 45 minutes to and from the treatment center. Another woman traveled over two and half hours to the treatment center making her entire treatment day, with travel, over 12 hours. Both these women found this to be very taxing, long and difficult. Another woman shared an experience where she travelled by air to her home community following her treatment and found this to be a very stressful and difficult experience. Following this event, she opted to relocate permanently to Winnipeg for the remainder of her treatments because of the physical demands of travel and physical challenges with travel.

I was still having a lot of chemo side effect...I just get hot flashes and you just get like dizzy and you're just like I don't know if I'm going to faint, like you just feel like it's, and it's an anxiously provoking like right here you can feel the anxiety, it's like I got to breathe through this. (A2, lines 1313-1318)

Chemotherapy posed many unique physical challenges for the women which would escalate needs in other domains. Once chemotherapy was complete, the women had a month to recover then start their radiation therapy. The women, who received Herceptin therapy, continued this treatment for another year following their radiation therapy.

1. 23 Radiotherapy. All women received radiotherapy as part of their treatment plan and would last from 17 and up to 33 days. Many of the women described the radiation experience as easy compared to the chemotherapy but other demands related to relocation or travel made it challenging. In addition, many of the women continued to experience expected side-effects that affected their quality of life. Fatigue was a common complaint associated with radiotherapy treatments. Fatigue was described as mild to severe and would affect women in many different ways. It also became apparent during the interviews that travel demands associated with radiation would aggravate the fatigue. One woman was required to travel 3 hours each way to and from treatment to Winnipeg for 25 treatments and reported fatigue to be her most difficult

side-effect from the therapy. Some women also were required to commute for radiotherapy without an escort. One woman, who had no-one to assist with travel, described her radiation experience as the most difficult part of her journey based on her physical symptoms. She described an incident where she was in a small accident in a parking lot causing damage to her vehicle and in hindsight wonders if she should have been driving at all. This woman felt that more assistance with travel is warranted based on travel safety concerns that are apparent when someone is feeling unwell.

But you know with the brain fog and being tired from radiation you don't think properly, you probably shouldn't have been driving. (C1-2, lines 480-482)

Radiation skin reactions were another commonly reported side effect of treatment which was described as mild to severe. One woman had all her treatments in Brandon and managed to drive home for the weekends. She experienced minimal problems and mild skin reactions. Conversely, different experiences were described by others in regards to radiation skin reactions. One woman required many weeks of home care support to help her care for the wounds following completion of her therapy.

I was burned, my whole chest, under my arm. Even onto my back. It was like it just slued off it was like a piece of meat. It was horrible. (C2, lines 855-891)

In addition, some of the women also commented on how painful it was to have the tattooed markings done prior to the start of treatment. Other less frequently reported side-effects to radiation included nerve pain and numbness at the site of the treatment, radiation changes to the reconstructed breast, breast swelling and nipple pain. Therefore, radiation was not without its challenges. Many other unmet needs in the supportive care framework were also identified when the women were receiving this therapy which will be further described.

1. 24 Hormone therapy. Hormone therapy was indicated for seventeen women as part of their treatment plan. Tamoxifen and Letrazole were the most frequently prescribed treatment. Extemestane, Eligard and Zolodex were other reported therapies. Additionally, three women had not started therapy at the time of the interviews to report side-effects. The women receiving these medications will remain on therapy from 5-10 years. Menopause symptoms were frequently reported side-effects of long term hormone therapy. Hot flushes, night sweats, weight gain, insomnia, and mood swings were some of the reported side-effects ranging from mild to severe. Women who were menopausal were more readily equipped to handle the side-effects caused by the hormone treatment as they were already experiencing the symptoms of menopause. The younger women who were pre-menopausal were more challenged by the discomforting symptoms. Another common problem described associated with hormone therapy was mild to severe joint or bone pain. It appeared that the many of the drugs caused this side-effect and reported by many women. Some woman reported severe bone and joint pain that was very debilitating. One woman who lived alone had a very difficult, debilitating decline following initiation of therapy. Following repeated visits to Winnipeg to see her oncologist she was switched from Letrazole to Tamoxifen with a complete resolution of her symptoms and now functioning independently at home.

It started at the end of January and I just found myself getting, my shoulders were more and more sore and I was taking more and more pain medication and it wasn't doing any good. I was able to do less and less. (C2, lines 944-947)

Some women reported that they were completely asymptomatic with the initiation of hormone therapy but were told that they could expect side-effects to occur as they progress on therapy.

The longevity of hormone therapy related symptoms were not explored in the study although many women expressed that their treatment journey continues for the duration of this therapy.

1. 3 Psychomotor Care Processes

Psychomotor care processes involves the skills and knowledge to manage fine and gross motor activities. Associative tasks may include activities such as walking, administering medications, manipulation of equipment, or performing a procedure such as a dressing change (Bastable et. al., 2011). Many mobility issues have been described associated with the physical side-effects that occur with the treatments. In addition, managing skills such as caring for post-surgical drains, post-operative arm exercises, Neupogen injections, and post radiation dressing changes were also tasks that complicated the experience for many of the women.

All the women were discharged with post-surgical drains following their surgery. The drains often remained in place for about a week post surgery and caring for drains was a challenge for the women. A number of the women lived alone and required home care, family or friends to assist. One woman described the need to have friend move in with her to help her manage post-surgery, but not all the women had this level of support.

My friend came and stayed with me and she did all the drains and you know made sure I was taking the medications properly...she was here for about two weeks” (C5, lines 943-945)

Some of the women were challenged to find someone to remove the drains in their rural setting because of lack of access to HCP who were skilled to perform this procedure. The women were often required to return to Winnipeg or Brandon to have the drains removed. As previously described, this woman’s surgery was complicated by a post-surgical abscess and then expressed an additional challenge to find someone to remove the drains in her rural setting since travel was not an easy option for her.

I had Homecare coming to do the dressing changes, check the drain, and then it was a big thing was whose taking the drain out, Homecare doesn't do it, Emerge won't do it, so somebody from Homecare ended up phoning and saying she's coming in to Emerge now, and that drain has to be taken out before she gets infected again (A4, lines 615-619)

A number of women were required to initiate Neupogen therapy to support them with the side effect of neutropenia. Administration of the injections posed some challenges in some cases. The women were either required to self-administer the injection or rely on family, friends, or home care. Some of the women opted to go the local CCP daily to have their injections done if the clinic was nearby. One woman, who lived alone, described a story where she was just too sick from her chemotherapy and expressed that going to the cancer clinic would take more energy than just doing it herself.

I was so sick I didn't care...I wasn't good at it. I'm not a good nurse I tell you. I wasn't good at it but at least if I went from one side of my tummy to the other this little bruise wasn't so bad and I could pick another spot (B2, lines 1048-1052)

Other women opted to have home care to help them with the injections if they did not have family to support them through this. This was mostly facilitated by the rural HCP and did not pose a significant obstacle for women who chose this option.

The women that experienced skin reactions related to the radiotherapy were often challenged with the need for daily skin care and dressing changes. Although this is a potential side effect for all persons who require radiation treatment some additional challenges associated with living rurally were noted. One woman relocated to Winnipeg for her treatment and developed the skin reaction by the third week of treatment. Her husband was not able to relocate with her because of work related responsibilities therefore she was living with a distant male friend. She voiced discomfort having him assist her with this personal activity.

So I even had XXX the guy that I lived with, I said please you have to put the cream on my back, I can't...I was uncomfortable with him touching me (A5, lines 1096-1070)

Another woman described an experience with severe skin reaction which required dressing changes for many weeks following her treatment. She was able to manage care of wounds with the support from her husband but did not have access in her rural area to dressings and equipment needed to properly manage her care. She described having to obtain a special order from her local drugstore but still developed ongoing challenges in obtaining the correct size of dressing. Having support and proper information to assist them with psychomotor activity alleviated some of the burden for the women but was not without specific challenges. Having improved home care services, support and resources in rural communities was a common suggestion made by many of the women.

1.4 Managing Emergencies and Other Health Care Services

Dealing with the ongoing physical needs related to the toxicity of treatment is challenging. Eight women talked about utilizing emergency services in their home community for such needs. Neutropenic fevers, rash, bleeding, dehydration, constipation, caring for devices, and a surgical abscess were examples that were described by the women. Access to emergency services or other healthcare services in rural areas to manage the problems would pose certain obstacles. Two women talked about limited physician services in their local hospital emergencies. In the first situation, the woman lived in a small town with a population less than 2,500 people. The hospital setting was very small with 14 acute care beds and limited diagnostic services. This woman made repeated trips to the emergency and at times a doctor would not be available. She also felt concerned about the lack of experience in cancer-related problems in her rural setting. In the second situation, the woman lived in a smaller town with a population of

less than 1,500 people. She described an experience where she was extremely sick following one of the chemotherapy sessions with no doctor on call in the local hospital.

Yeah, I got an infection in my gums. I woke up one morning burning hot and it was a -40 day and I took my temperature, it was 102...My gums were bleeding like crazy.... Hum, so they finally caught the doctor, there was no doctor on call. The doctor on call for this area was on his way to Winnipeg. So they caught him on the road and he prescribed some um.... pills (C2, lines 683-690)

Other women talked about inexperienced staff in the hospital emergencies. One woman accessed Brandon emergency department and voiced frustration over limited experience with central venous devices. She would often have to guide the HCP through the process or refuse care from an inexperienced nurse. Based on some of the challenges the women would face, they would often wait until they could attend their local CCP for most of their health care needs or contact Winnipeg or Brandon for direct consultation with their oncology specialists. This certainly posed challenges on weekends or evening when emergencies could occur. Improvements in emergency care and qualified, knowledgeable HCP were other recommendations made by the women.

1.5 Physical Domain Summary

In summary, the physical domain challenged the women in many ways. Although symptom of illness and physical side-effects of cancer therapy are expected for all women living with breast cancer, additional obstacles occurred related to living rurally. During initial presentation of illness, challenges related to the travelling mammogram program or delays in diagnosis due to winter driving existed. Other patient and medical delays also occurred. During the treatment phase of illness, travel continued to be a challenge related to exacerbation of physical symptoms such as fatigue, pain or skin reactions. Additionally, travel safety concerns were apparent related to symptoms such as overwhelming fatigue, “chemo fog” or not being able

to wear a seatbelt. Access to experienced and qualified HCP or emergency services to manage their complex physical needs was also a worry for a number of the women. As a result, the additional burden on family and friends for additional travel or help them care for complex physical needs resulted. However, the positive role the CCP and home care supportive services were addressed in many of the interviews and helped the women transition through the physical demands that they encountered. A number of recommendations made by the women were highlighted in this domain.

Informational Domain

The operational definition of this domain, defined by Fitch and colleagues, states that Informational needs are based on “the need for information to reduce confusion, anxiety and fear; to inform the person’s or family decision-making; and to assist in skill acquisition” (Fitch, 2009 pg. 18). The findings in this domain have been categorized according to three broad topic headings which include health care providers, informational resources and supportive programs and services. The following table illustrates the heading summary in the informational domain.

Table 2: Informational Domain Summary

<p>2.1 Health Care Providers</p> <ul style="list-style-type: none"> • 2.11 Rural Family Doctors • 2.12 Oncology Specialists • 2.13 In-Patient Hospital Staff • 2.14 Nursing • 2.15 Nurse Navigators • 2.16 Interdisciplinary Professionals
2.2 Informational Resources
<p>2.3 Supportive Programs and Services</p> <ul style="list-style-type: none"> • 2.31 Western Manitoba Cancer Center • 2.32 Telehealth • 2.33 South Central Cancer Resource Center • 2.34 Home Care
2.4 Domain Summary

2.1 Health Care Providers

The women had a number of different health care providers who provided a primary source of informational support at different points of time during their journey. Rural family doctors, oncology specialists, in-patient HCP, oncology nurses, nurse navigators, and interdisciplinary professional involvement were discussed in the interviews. Although many of

these providers were viewed as a critical part of their care there were also challenges that presented related to living rurally that will be highlighted in the following sections.

2.11 Rural family doctors. For all of the women, entry into the medical system began through rural family doctors. These physicians often facilitated the initial testing at first suspicion of cancer. They notified the women of the abnormal mammogram findings and often became the primary source of informational support early in the diagnosis. Additionally, once the women completed treatment, the family doctors would resume primary care in the follow-up phase of illness. A number of women had long-standing family doctors who were attentive, supportive, and expedited their care at first sign of illness. Many of the family doctors were also linked to the CCP program or had additional experience with cancer and therefore were able to provide the informational support needed for the women throughout their illness. It became apparent that those who had trusted, experienced family doctors, mostly felt their informational needs were met. One woman, who lived one hour outside of Winnipeg, did not feel the need to meet with her oncology team, felt the trip was an inconvenience and described how her informational needs were met through her family doctor.

*I have a great doctor, so you know he was, he was very, very compassionate and you know he, he did as much as he could to explain things and how, how it was going to go” (lines 276-278)
“some days I just thought oh my God I’m going to be in there (in Winnipeg) for like 10 minutes and it’s you know I have to drive all this way and then drive all the way back home. (C5, lines 781-783)*

Not all the women felt as comfortable obtaining information from their family doctors and described them as generalists or were concerned with their lack of experience in cancer-related problems. One woman described feeling appreciative to have a family doctor but would often call directly to Winnipeg when she had cancer-related questions.

It is good, but you know, you know he's not, like he's, he's, he's a GP, like you know darn well he's not the cancer doctor, he's going by what he reads and what he gets from your other doctor. (B2, lines 610-613)

Receiving the diagnosis was a very difficult time for the women. It was often described as “terrifying or shocking” when the biopsy results were revealed. Many of the women had little or no experience with the health care system and often expressed that they did not know what to ask or where to turn for help. One woman described feeling upset with the lack of information she was provided by her family doctor on the visit when she received her diagnosis. This woman talked about how important it would have been to be linked to a navigator or social worker early on in her diagnosis when she felt the most vulnerable.

I'm told I've got cancer and then I'm left out to hang by myself. Like the doctor did not tell me there's a counsellor here, there is a navigator here, there was no pamphlet. He handed me a piece of paper and then said, I want the marker, like I said blood work, EKG and a CAT scan done and that was basically, and I didn't know there was like a cancer, breast cancer clinic, like I knew nothing...zero. (B4, lines 2350-2355)

There was also the challenge of not having a long-standing family doctor. Many of the women described changing family doctors frequently during the course of their cancer journey and therefore were required to seek informational support through other means. Women also described challenges related to lack of physician support when the need for emotional and informational support was heightened. One woman described having a family doctor for a very short time and felt a lack of compassion when the diagnosis was confirmed. Scrambling to find a family doctor to take on her care escalated the stress this woman experienced but once she found someone she could count on she felt more comfortable having both her informational and emotional needs met. Gaps in communication between rural family doctors and Winnipeg

specialists' were also described in a number of the interviews. This often led to the women having to provide the family doctor with updates regarding their progress and would make it difficult for the family doctors to provide additional information and support that the woman required at various points of time during the journey. Improving communication between the rural and urban sites was a common recommendation made by the women. Moreover, family doctor support was also essential at the completion of therapy when transition back to primary care was implemented. All the women were asked to describe how they felt about their follow-up care. Many of the women happily returned to their family doctors and were pleased that they no longer were required to travel. Whereas, others voiced feeling ambivalence when follow up from oncology specialists were no longer needed. However, transition of care and follow-up was not thoroughly explored in this study since most of the women were in the early phases of this process but the need for a smoother transition of this process was frequently described.

2.12 Oncology specialists. All the women met with a surgical, medical, and radiation oncologists during the course of their journey. While the information received from the specialists was vital, the appointments were often compounded with many other emotions making the information very difficult to process. In addition, these visits were at times when their informational needs were heightened and the delivery of the material was highly complex. The inability to retain the information they were receiving became a common concern expressed by many of the women. The impact of travel and condensed appointment schedules also compounded the ability to process complex information. One woman described travelling 4 hours per day for many days for tests and appointments and found the information she was receiving very overwhelming.

There's so much going on in your head that I just didn't know if I could process any more information at that very time. I had a bunch of more tests I had to get run into Winnipeg, a MUGA Scan and we were going for MRI's and it was just constant like just constantly going back and forth for tests. (D2-2, lines 467-470)

The women continued to express an urgency to proceed with treatment despite feeling overloaded with information. Some of the women emphasized that “need to know” information helped them cope with the amount of information they were able to retain. Additionally, a “one step a time” approach was often required to help the women process information. One woman talked about using this approach to protect her from feeling too inundated with information. Alternatively, women described feeling unfamiliar with cancer treatments and services creating additional uncertainty about what they should know or what to ask their specialists. Some of the women subsequently reported that everything was happening so fast in the initial stages that there was pressure to make treatment-related decisions quickly. One woman was required to relocate to the city for a condensed week of appointments and described feeling so rushed which resulted in making a regretful decision to proceed with breast reconstruction.

Everything just happened so fast, I started thinking like oh what happened if I feel like because I don't have breasts, like everything just happened so fast that I actually I wouldn't have gotten reconstructed...I had to make up my mind right there when they were telling us and it's like uh, like it was all so fast. (A1, lines 1302-1313)

Therefore, informational needs at the early stages of illness were highly complex especially in combination with the emotional impact of a new diagnosis of cancer, travel and re-location. Many women talked about the need to record sessions, use plain and simple language in informational materials or use of telehealth to provide follow-up educational support is warranted. Another woman recommended having information mail out in advance of specialist appointments she would feel more prepared to ask specific questions.

Support from family or friends were paramount to assist with processing and retaining information. A number of the women had a support person who accompanied them to their appointments with the specialists. A number of women explained that the role of a support person during these meetings was vital to help them process the information they were receiving. However, there were some women who were required to attend appointments alone. Many of these women were widowed or single with a less extensive immediate support system. Northern women who were travelling to the city through NPTP were rarely able to have an escort accompany them for these initial appointments unless they covered the cost independently. One woman reflected that her inability to retain information from specialists was directly related to travel demands and the lack of a support person to escort her to the city. In this situation, the woman was capable of travelling alone and she did not have the financial means to have family accompany her. Improving the use of family escort was a recommendation that was frequently suggested.

Yeah. I think they left out a lot of the stuff, I don't know maybe I wasn't paying attention, they all, people always told me well you should have had somebody with you there so you know they could ask questions that you don't think of...Like sometimes I was so tired from being on the bus all night and then I just wanted to just lay down and sleep....I think that was the only part that bothered me the most is being alone. (A4-2, lines 266-272)

Meetings with the radiation oncologist were not a focus of discussion as the women described feeling much more comfortable with the information they were receiving and had the opportunity to prepare themselves in advance by reading materials or talking to others about experience. Furthermore, heading in the radiation phase of the journey, issues surrounding travel demands, relocation or other practical or social concerns often became the focus of their

attention. Less concern was placed on the physical problems associated with the radiotherapy treatment and informational needs from the specialist.

2.13 In-Patient hospital staff. Women described impact of care and support from in-patient and emergency nursing and physician staff and some challenges unfolded during the interviews. The surgical experience amongst the women varied. Some of the women felt well cared for and informed about the process and discharge procedures. Whereas others, described feeling ill-prepared to leave the hospital and did not have the knowledge to manage their post-surgical needs. Many women expressed feeling uncomfortable and inexperienced to care for the post-surgical drains. One woman, following a bilateral mastectomy with reconstruction, described a story where an in-patient nursing staff member provided her with information in regards to care of her post-surgical drains. At the time she and her husband were not ready to process the information and were ultimately discharged without additional discharge teaching or homecare support.

Well she was very rude and insistent with all of my drains with me doing it my husband doing it the 2nd day after surgery Well....she has done this so many times...No I've never done this before. (D1, lines 257-263)

In an alternative situation, a woman described same day surgery and discharge following her lumpectomy and received limited discharge teaching including instruction on post-lymphedema prevention exercises. She has since developed some associative problems with the affected arm and currently seeking care from a physiotherapist in her home community. Another woman chose to have surgery in Winnipeg based on the quality of surgical expertise and received lack of information surrounding her discharge time and date. This situation caused added stress for her and her husband and a very uncomfortable three hour drive home to her rural community.

So there was a lack of information...the girl at the desk 'cause she told ...and they're like no, she'll be getting discharged. So that was concerning 'cause I'm literally an hour before I'm going into surgery I have no idea when I'm coming out, where I'm staying, or what's happening. We are from rural Manitoba; you are discharging me when you told me that I was staying in for two or three days. (B3, lines 900-907)

Many of the women talked about how important it is for urban health care providers to consider some of the implications around living in rural setting such as travel, limited access to services, or homecare arrangements that may be required.

Another challenge described included limited access to inexperienced healthcare providers in rural non-cancer settings. One woman described having to explain care of her central venous line (CVL) to inexperienced emergency nurses. Another woman described a situation where she was seen by an inexperienced doctor in her local emergency for a FNE and prevented admission by linking the emergency physician to her cancer specialists. From an informational perspective, the woman would often need to take on the role of self-management of their care with rural HCP because of their inexperience with cancer-related problems. Whereas, it was often felt that the care providers should be providing them with the informational support and services that they required. Alternatively, a number of women talked about living in a rural setting as a choice and accepted some of these challenges as inevitable.

2.14 Oncology nursing staff. The role of oncology nurses in Winnipeg and the rural CCP was positively discussed by all of the women. The nurses in Winnipeg working in the CCMB clinics had a lesser role in the overall care compared to the nurses in rural CCP. Although, many of the women talked about how important it was to have nursing present during the meetings with the oncologist. These nurses would often spend additional time to provide further explanations or answer questions. Many of the women talked about how they appreciated

open access to the Winnipeg oncology nurses by telephone during the treatment phase and into the follow-up phases of illness. However, as the interviews unfolded, the informational and supportive role of the oncology nurses in the rural CCP sites became very apparent. Each of the women was asked to compare the difference in nursing care from a rural and urban perspective. A personal approach to care was a common theme noted in many of the interviews. However, the role of the nurses and other staff as a source of information was also very important.

I think the health care in the local community was more personal. I found whether it was my family doctor Dr. XXX, the nursing staff or, or the social worker as much time as I needed to be with them, to ask them questions...And if I came home and then had a question I could pick up the phone and they would talk to me. The quality, the care in the city, I would say was excellent you know no, no problem about that. It was just a little impersonal” (C4, lines 1245-1251)

Alternatively, a number of challenges were also identified in the interviews. Women talked about how busy the rural nurses were and they did not always have the time to spend with all the people in their care. The women also described environmental obstacles such lack of physical space and close quarters between patients. This would often present challenges for the nurses to have personal discussions that may be necessary. Additionally, two women talked about receiving chemotherapy treatments in both urban and rural sites and described receiving conflicting treatment-related information from the urban and rural nurses leaving questions in regards to the rural nurses' expertise.

2.15 Nurse navigators. Nurse navigators are positioned in many of the rural settings across all RHA and WCCH. Nurse navigators provide informational support and counseling as a primary part of their role. The women who had access to navigator support during their journey expressed the service as highly valuable. Ten women were unaware that the service exist or found out about it later in the journey when their information and liaison needs were decreased

and therefore never accessed the service. Rural navigators were utilized by women in the IEHA and PMH whereas, women from all regions accessed navigation services from WCCH. Rural navigation was more important in the early part of the journey when the women required information about cancer-related processes and services. Once the women were part of the CCP in their area, the nurses in these locations became the primary contact person and navigation was no longer utilized. The seven women that utilized navigator services at WCCH described a different experience. The navigator became an important source support throughout the entire journey and a consistent person to talk to through all the transitions in care.

“I needed someone to talk to, that was not my husband, that was not my parents, someone that I could completely be honest...having a navigator at the beginning I think is a critical thing for patients...a navigator can be your lifeline and they’re your lifeline through all the different transitions of care. You know you may have a surgeon, you may have a medical oncologist, you may have a radiation oncologist and so all of the nurses are different, all of the doctors are different, but the navigator can be your constant” (B3, lines 580-592)

Two women learned about navigator services later on in their journey and both expressed how important the service would have been when their informational needs were heightened. It was apparent as the interviews unfolded that access and awareness of navigator services was fragmented across the regions of the province. As well, many of the women were unaware of the service provided by WCCH which is a service that stems far beyond navigation services by providing many other informational tools and peer-peer supportive services.

2.17 Interdisciplinary professionals. The women from the PMH had access to support from many disciplines including pharmacists, social workers, dieticians and spiritual care workers and their expertise and knowledge was highly valued. Unfortunately, not all women from the other regions had access to these services. All the women were asked to share strategies

or difficult aspects of their journey. While answers to these questions were variable, a common thread developed related to limited access to interdisciplinary care which would have been highly valued. One woman expressed feeling fearful throughout her journey and talked about how beneficial it would have been to have weekly counseling when she was most afraid. In an alternative situation, the woman had many concerns and questions regarding finances, travel, child care, work and sick leave and would have benefited from the informational support from a social worker. When reflecting back on their journey during the interviews, a number of the women talked about how important it would have access to services from other disciplines but during the time they did not even consider it.

Some of the highlights that I think stand out for me are like the, the people who are missing from the healthcare team, that even though the role of them might not be as important in the beginning, I still think it's an important piece to have them involved...physiotherapy is huge and even dietician...to have that role as a part of that team. (A2-2, lines 1888-1892)

Other women could have had accessed interdisciplinary care in Winnipeg if they wished but mostly opted out because time and travel would be required. Increase use of interdisciplinary care was a recommendation that was frequently noted in many interviews.

2.2 Informational Resources

The women had access to or were provided with many different informational resources which included written materials, educational sessions, books, and self-instructional materials. Additionally, some of the women talked about taping their appointments with their specialist so they could re-listen to the appointment at a later date and found this very helpful. There were various opinions on the use of these resources. Moreover, how or what the women wanted to learn also varied. Some of the women talked about how useful it was to have multiple sources of

written or on-line information. One older woman kept meticulous records including appointment details, diagnostics information handouts, test results, prescription details, and journal submissions which were shared during the interview. She also utilized South Central Cancer Resource Center and the internet to seek whatever supplemental information she required and felt empowered surrounding herself with resources.

“Well like this book has so much stuff in it and it’s not all in here, I have a filing cabinet with a drawer that has a lot of resources for cancer. I read them all, I’ve read them again and again, I went online and read everything that was available there” (D5-2, lines 977-980)

During the course of the interviews many detailed record keeping strategies similar to this were observed, which included the written materials provided by their HCP. Conversely, alternative views on written information were also described. One woman talked about wanting to know how to stay well and informed about next steps while all other information was unimportant to her. Alternatively, some women found the resources overwhelming and put it aside without reading it. One woman talked about her dislike of reading and had her sister interpret the materials for her. Another woman did not receive any written information until she had a visit with the medical oncologist which left many unanswered questions which she found upsetting. Additionally, a number of women utilized educational sessions or videos offered by WCCH or Breast Health Center and there was conflicting messages on their usefulness.

I went to an information seminar and basically the lady that was facilitating it just read the pamphlet ..and then we got cookies and coffee ya so I read the pamphlet.....I don’t need to drive all the way to the city for this. (C1, lines 823-828)

Journaling also proved to be a very useful tool, to keep detailed records of appointments, diagnosis information, treatment modalities or test results. Women were happy to share their journal as we discussed their experience which proved to be an important means of processing

information and keeping track of the complexity of the experience. Self-learning was also a strategy utilized. Some women used the internet as one of the primary source of information, whereas others felt it was important to avoid the internet or only seek sites that they were directed to use. Utilizing a variety of informational resources often became useful for the women but more direction on what to access was often required. It became apparent throughout the interviews that informational needs of the women were variable and tailoring information strategies towards individual learning needs is an approach that should be utilized by all HCP.

2.3 Supportive Programs and Services

Access to other supportive programs and services varied across the province. Western Manitoba Cancer Center, Telehealth, South Central Cancer Resource Center and Home Care were the services that were discussed by the women.

2.31 Western Manitoba Cancer Center. The women living in the PMH had access to care in Brandon which was considered comparable to Winnipeg. Although travel was still necessary for four of these women, it was considerably less than travelling to Winnipeg. The women had access to interdisciplinary teams of oncology professionals, navigation, telehealth, and other services. One woman described having all her care in Brandon and felt cared for throughout her entire journey. All her informational needs were met and she only required a few trips to Winnipeg to meet with a medical oncologist. Some of the women were still required to attend appointments in Winnipeg and one woman relocated for radiation but significantly less travel was required. The role of Western Manitoba Cancer Centre, Brandon was positively described.

2.32 Telehealth. Telehealth was accessed by all of the women in the NH and PMH. Some of the women from the SHSS and IEHA reported that Telehealth was not offered. The

biggest benefit of this means of exchange was the ability to remain home and negate the need to travel. However challenges exist including fragmented conversations.

I don't think it's the same as person to person. No, I, I, yeah, and you feel I think more awkward talking to a machine, you would probably be more open or I would be more open on a, on a person to person rather than, rather than on telehealth. (C2-2, lines 908-911)

Telehealth meetings were not always a preferable method of communication when physical symptom and informational needs were heightened and one woman described regret not making the trip to Winnipeg when faced with significant chemotherapy-related toxicity. Telehealth was much more positively described in the follow-up phases of illness when the informational and physical needs of the women were not as significant. Increase use of this mode of service delivery was a recommendation made by many of the women.

2.33 South Central Cancer Resource Center. This service is offered in two areas in the SHSS. The women had access to knowledgeable staff, extensive information materials, head coverings, and other supportive services. One woman accessed a community run peer-to-peer support group for cancer survivors from the knowledge gained from this community resource center. This proved to be a unique and important resource for the select number of women who lived in this region and benefited from this service.

2.34 Home care. Women from IEHA, NH and SHSS described experiences with access to home care service for administration of injections, dressing changes or caring for post surgical drains and the experience was described positively. One widowed woman who lived alone in need of home care assistance described a very positive experience. Access to experienced nurses in their home to answer their questions, provide additional support and assist in the management of their care proved to be important service. However, access to home care was not offered in

some setting which added to the complexity of the experience and heightened the learning needs of the women.

2.4 Informational Domain Summary

In summary, the information needs of the women were complex and many compounding variables existed. Information was retrieved from a variety of HCP including family doctors, oncology specialists, in-patient hospital staff, urban and rural nurses, nurse navigators and interdisciplinary professionals. A number of factors would impact the women's ability to process the information they were receiving including escalating fears, long travel days, multiple condensed appointment schedules, complex information, or lack of support person available to attend the appointment. Access to family doctors appeared to be fragmented across all regions of province and communication between rural and urban sites also proved to provide challenges. Additionally, it also became apparent that rural HCP or hospital staff with limited knowledge in cancer-related problems became an additional challenge expressed by a number of women. As the interviews unfolded the role of the nurses and staff at the CCP with cancer expertise was vitally important for the women to meet their informational needs but challenges exist based on the lack of physical space or privacy for personal discussions in the rural sites. The use of nurse navigators or access to other interdisciplinary professions was limited and would have proved to be very useful. Many informational resources or other supportive services were also utilized and a variety of opinions on the usefulness was described.

Social Domain

The operational definition of this domain, defined by Fitch and colleagues, states that Social needs are based on “the need to relate to family relationships, community acceptance and involvement in relationships” (Fitch, 2009 pg. 19). The findings in this domain have been categorized according to four broad topic headings including social networks, rural life, communication with others and social isolation. The following table illustrates the heading summary in the social domain.

Table 3: Social Domain Summary

3.1 Social Networks
3.2 Rural Life
3.3 Communication with Others
3.4 Social Isolation
3.5 Domain Summary

3.1 Social Networks

All of the women were asked to describe their family life, sources of support, relationships, and scope of their social networks. A vast scope of the social networks was described by the women such as primary and extended family members, friends, neighbours, co-workers, community members, spiritual communities, or other health or social services.

Marital status, including a supportive husband, was a very important factor in how the women described where their primary supports came from and where it extended. Eleven of the women were married and lived with their spouse. Many of these women reported that their spouse was their primary source of support during their illness. The men often became an active participant in the cancer journey which included many roles such as attending appointments, driving the women to the city for treatments, providing additional physical support, taking on

additional roles in the home or other supportive activities. As well, the emotional aspect of having a supportive husband was often positively expressed especially during difficult times in the journey. One woman talked about feeling very vulnerable and fearful during many points in time and leaned on her husband for the emotional support she required.

He's a rock, just a rock you know, I, and you know there were times when even before the surgery when you're waiting...I would just balling my eyes out, you know it was really very emotional. But he was a rock you know if you need to cry you need to cry, come here, sit on my lap I'll give you a hug, hold you, you cry as long as you want, get it all. (C4, lines 446-452)

Many men were either self-employed or retired and were able to facilitate the extra time for travel. One of the men chose to retire based on his wife's diagnosis so he could provide her with whatever support she needed. The women often chose to travel versus relocate for radiation therapy based on the assistance they received from their husband for travel. One couple was able to relocate together which was a more convenient option. Five women were required to relocate without their husband and described an additional sense of isolation because of this. One woman expressed that being separated from her husband while receiving her radiation was extremely difficult and overwhelming.

So he came with me and then he left to go home and I remember just lying there and I just burst into tears out of nowhere, its, it's overwhelming. And now I'm here in the city by myself without him. (B4, lines 1461-1464)

Two women had less emotional or practical support from their husband and therefore leaned on other family members or friends to assist where needed. One woman talked about how her husband was struggling emotionally with her diagnosis and became physically ill as a result. In this situation, he was unable to travel, drive or support her emotionally so she leaned on others

where needed. Another woman, who was the primary income earner in the family, and with her husband who was unable to assist she leaned on her sister and son to help her pay her bills.

Many of the women also described multiple levels of support which included children, adult children, grandchildren, extended family such as brothers or sisters and parents, friends, neighbours, co-workers and community members. Additionally, a number of women either lived with or had close contact to younger children or grandchildren which was often described positively. Children or grandchildren provided a positive distraction or helped validate the importance of family. Many of the women cherished the opportunities that they could spend time with their children or grandchildren in their lives which further helped them cope with their diagnosis.

Nine women were widowed, single or separated or divorced from their spouse. Some of these women lived alone and others lived with extended family members such as adult children and grandchildren. For the women without a husband, primary supportive networks were described as family, friends, extended community members or health care providers. Some women relied heavily on extended family members for additional support. One woman lived with her daughter and granddaughter but her sister was able to travel with her to many of her medical appointments. She described these primary family members as her most important source of support.

*I mean first of all is to have your, your support system, family, 'cause that certainly is important when you're you know not feeling good after chemo and, and you know helping with your everyday life at that point. So I think that's what everyone really needs first and foremost.
(A3, lines 723-730)*

Some of the women had extensive family networks that offered support while others had limited and smaller circles of family support. These women would often need to rely on friends to assist with some of their needs. As the supportive networks diminished, extension of support would often be directed elsewhere. One woman was in the process of a divorce and had limited support from her sons. When asked what made her feel the most supported throughout her illness she talked about her co-workers in the community hospital where she worked and the HCP providers who contributed to her care. Six women lived alone but were supported by friends or family at different times during the illness. However, many of these women felt it was easier to be alone when they were feeling unwell because they did not have to worry about others. Women who live alone were also required to hire additional help for travel or household needs or the women would simply manage these activities themselves. One woman who lived alone talked about one of the most difficult aspects of her journey was to ask for additional help from others.

I really found the hardest that I had to rely so much on other people...you know you just feel like you are a burden to them...they don't make you feel that way...but I felt that way. (D4, lines 873-876)

Therefore it is apparent during the course of the interviews that the women who lived alone or had limited family supportive networks that roles related to the household duties became a mounting challenge which will be further discussed under the practical domain.

3.2 Rural Life

All of the women were asked to describe life in a rural area and what rural living means to them. Unquestionably, there were many different answers to these questions but some common descriptions emerged related to environment and community atmosphere. One woman described rural life as peaceful, quiet and full of community support. A further description of rural life included a strong sense of belonging and support from neighbours, friends or members

of the community. One woman who has lived in a small town most of her life expressed enjoyment knowing everyone in her community. She had many supportive networks beyond family extending into the community that provided her with support during her illness.

And then smaller places hey like everyone knows you and that, it's nice, I like that (A1, lines 352-353)

The feeling of community support was often positively reported. Another woman described an entire community that rallied together to raise money for her to help with her travel. This proved to be instrumental in her journey as the financial burden of this illness was a mounting problem. There were also drawbacks to living in a small community noted in a number of the interviews related to lack of anonymity. Privacy was very important to this woman and she was challenged to keep her personal journey concealed.

Yeah, cause everyone knows everyone's business. That's the way it is. Everyone knows everyone's business... and if you are a private person and you want to keep things private it's pretty tough... and usually it gets out and it goes like wildfire. And lots those things are personal. (B1, lines 1649-1652)

The CCP also added a unique variable to living with cancer in a rural area. When comparing the care from Winnipeg to the care from a rural setting it was often described as more personal, relaxed pace and the staff was more accessible to provide the support and facilitate the needs of the women. The women talked about developing deep bonds and therapeutic relationships with their caregivers and would get to know them on a very personal level. One woman talked about how the nurses would come by her home to see how she was feeling. Another woman described nurses calling her personally to check in and make sure she was managing. However, knowing your caregiver would also pose some interesting obstacles. Women spoke about having past or present social relationships with their HCP. One woman

described providing child care for her nurse when she was younger. Other social relationships with caregivers varied which included friends, coworkers, congregation members or casual relationships. Additionally, the social aspect of having care in a rural CCP was viewed both positively and negatively. For the majority of the women the close quarters in the CCP promoted a sense of community and support with the other cancer survivors. One woman described enjoyment having treatment in her home community and felt supported in this intimate and close setting.

I loved it...it felt like one big happy family....we are all in this boat together...I'm not the only one who has to come and take chemo... every once in a while someone else will show up that we don't recognize and umm...so then we'll greet and introduce ourselves. (D3, lines 1110-1113)

Alternatively, women who were more private felt quite uncomfortable in this setting. Six women talked about limited privacy or not feeling up to having discussions with other patients. One woman felt very vulnerable in this setting and asked for a private room whenever possible to limit any contact with other patients receiving treatment. Another woman described discomfort knowing community members or people from her past having chemotherapy at the same time. Overall, the benefits of being able to stay close to home for their chemotherapy treatments positively outweighed any of the obstacles of privacy or lack of anonymity which commonly occur in rural settings. However, improving aesthetics and private spaces in CCP was recommended by many.

3.3 Communication with Others

Considering the vast scope of social relationship and nature of the close knit community atmosphere it was discovered when faced with a diagnosis of cancer, communication with others

became another obstacle as the women proceeded through their journey. Telling others about the diagnosis posed some challenges for the women. It was often described that readiness to talk about the diagnosis prior to speaking to other family or friends was important. One woman kept the news between her and her husband at the initial stages of her diagnosis until she was ready to tell her immediate family. She talked about news such as this spreading quickly in rural communities and she wanted to ensure her family heard the news firsthand. It became important that the women had to control over how and when people were told of the diagnosis because their concern that the news would spread very quickly. One woman with young children concealed the news from others until she found a way to talk to her children. She was very worried that the children might hear something that would make them feel afraid. Other women chose to tell select people and keep the information from others. One woman was a primary caregiver for an aging parent with early stage dementia and was able to keep the diagnosis a secret despite seeing him on a regular basis. She did not feel she should burden him with the news. Another woman was the primary caregiver to two grandchildren and felt that they were too young to understand the meaning of the disease. Other women described sharing the news with immediate family only because it is a very personal and private matter. She remained very selective who she talked to about the illness throughout her journey.

They want to talk to you....and you know what.....I'm not ready to share my experience with just..... It has to be the right time....for me it has to be the right time....if I'm feeling up to it. (D1, lines 577-579)

Dealing with family member's responses to the cancer diagnosis at times proved to be problematic. If the family members were supportive then the journey was often more manageable. If there were opposing views on the decisions being made then the course of illness became much more complicated. One single woman described a situation where her sister

challenged many of her treatment-related decisions. She described these opposing views as one of the most difficult aspects of her cancer journey.

I wasn't making any right decision....um...so you really don't need that....when you're going through this....and I had one sister...well actually a relative asked me "how did your sister support you"and I said "well it was like this....she was very good with bringing me some food.....they brought me the church CD's...but when it came to the decisions that I made with cancer...I didn't make one right one for her." (D4, lines 222-226)

Another woman described conflict between her and her daughter who was opposed to her having chemotherapy. Her daughter was unable to attend appointments with her mother because of travel causing additional time away from work and therefore spent much of her time looking up treatment options on the internet. This family was able to work out their difficulties after a period of time but it added to burden this woman was feeling as it was very important to her that her daughter was onboard with the treatment decisions she made. In an alternative situation, the women's daughter lived in a different province and was adamant that her mother should not proceed with chemotherapy. It took time for her daughter to come to terms with her mother's decisions.

Other communication challenges included receiving inappropriate comments from others. One woman talked about being approached by complete strangers at different social events enquiring about her diagnosis. She subsequently isolated herself from events in her home community to prevent this from occurring. Another woman described casual conversations with people in her community that she would find very distressing.

And the worst thing people can tell you is, when you're going through this, oh my friend went through this and this is what happened and it came back. And you know as soon as I would hear that from my feet right up I would just feel this anxiety. People, I don't know they don't

mean to be insensitive, but you don't want to hear that and I kept hearing that. (B4, lines 1606-1610)

Alternatively, relationships with other survivors were also very positively described. One woman attended a support group on a regular basis in her home community. This was a very important validating and supportive activity and she plans to continue as long as she can.

"You go around, we sit at a big round table...You listen and you hear what other people that had the same problem as you do. What they've been through this last 3 weeks and you think... wow..... that's happened to me to so that's just normal. (D5, lines 794-801)

Other women also talked about developing deep bonds with other cancer survivors which will be highlighted in other domain discussions. Therefore, positive aspects to relationships and communication evolved as the interviews unfolded. However, some of the communication challenges described would lead to the women further isolating themselves in their communities.

3.4 Social Isolation

Considering the complexity cancer treatment, access to cancer services, vast scope of social relationships, obstacles living in a close knit rural community, and challenges surrounding communication about the illness it was often found that women felt isolation for a number of different reasons. Firstly, women would feel isolated because of the need to relocate for treatment. The women who were required to relocate alone to the city for radiotherapy were often feeling a sense of loneliness or isolation while missing their family. One woman from a northern community was not able to bring an escort with her for many of her trips to Winnipeg. When asked to describe the most challenging part of her journey she talked about isolation and loneliness she felt when she relocated to the city alone.

I don't want to be here, I want to go home, you know I was kind of being, I was, some days I was being a big suck, so then I'd walk and kind of cool down a little bit, have a nap, think about going home

later, have a nap, okay. Look at the kids' pictures, okay that's why I'm here; let's just get it over with. And then my grandson, that bothered me, I missed his birth. (A4, line 1029-1034)

However, some women did enjoy their time alone but this mostly proved to be a very challenging time for many of the women. This sense of isolation from family not only affected the women who were relocated but it affected the family members who remained at home. Additionally, women would often describe a sense of isolation related to leaving the community for long periods of time. One professional woman was unable to work during the course of her therapy because of long periods of time where she was required to relocate to Winnipeg and described professional isolation and lack of engagement in her community.

Many other reasons the women would feel isolated. First, the very nature of cancer treatments and side-effects can cause isolation. Fatigue, neutropenia or other physical ailments resulted in isolation. Second, women also described the need to isolate themselves to avoid many social situations. A number of women purposely avoided all amenities in her home community for fear they may see people that they know to avoid engaging in any conversation surrounding their illness. Third, women also described as sense of isolation related changes in relationship. Women would often feel that others would avoid them because of the diagnosis.

I had some friendsbecause I remember reading on it.... some will gravitate toward you and some will run from you..... and I had one friend that never really called me or paid attention to me all through it...They're scared of you or something... Some people gravitate towards you and know what to say and some people have to run because they can't do it..... and that is so true, so true. (B1, lines 1609-1615)

Another reason for isolation was related to the stigma of the diagnosis of cancer. Women talked about the physical changes such as hair loss that would lead to isolation. Whereas, others felt shame related to being diagnosed which would prove to be further isolating.

I kept saying it's not my fault, but yet I felt shame and that's why I, one reason why I didn't want to go out in public is because I felt shame and, and I don't know where that come from. (B4, lines 1720-1722)

The level of isolation would also impact how the women coped with the illness and the emotional impact of their journey. The practical needs would be markedly affected based on the support they received. It also really allowed the women to re-examine or re-evaluate what social relationships were important in their lives. These concepts will be brought into other domain discussions.

3.5 Social Domain Summary

In summary, the social needs of the women proved to be very complicated and many challenges exist because of the very nature of where the women lived. The women described a vast scope of social networks including immediate or extended family, friends or community members and utilized the support they needed at different points of time during their experience. The scope of support networks also varied among the women based marital status or available family or friends. Living alone was viewed both positively and negatively and posed other practical challenges. Additionally, HCP in the rural setting also proved to be an important source of support for the women and was often viewed positively. Women talked about the love of rural life because of the strong sense of community atmosphere however this would also posed specific obstacles. Lack of anonymity, invasion of privacy or communication challenges with others would often lead to feelings of isolation. Furthermore, relocation for treatment, physical

challenges of illness and avoidance of public places or other people would also prove to be isolating. Other unique obstacles to rural life included news traveling quickly, knowing your caregivers, having treatment with known community members or positive or negative communication surrounding illness.

Practical Domain

The operational definition of this domain, defined by Fitch and colleagues, states that Practical needs are based on “the need for direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person” (Fitch, 2009 pg. 19). The findings in this domain have been categorized according to seven broad topic headings including activities of daily living, instrumental activities of daily living, provision for family, travel, accommodations, employment and financial implications. The following table illustrates the heading summary in the practical domain.

Table 4: Practical Domain Summary

4.1 Activities of Daily Living
4.2 Instrumental Activities of Daily Living
4.3 Provision for Family
4.4 Travel <ul style="list-style-type: none"> • 4.41 Travel Demands • 4.42 Travel Safety • 4.43 Road Conditions • 4.44 Appointment Scheduling • 4.45 Driving in Winnipeg • 4.46 Northern Travel
4.5 Accommodation
4.6 Employment
4.7 Financial Implications <ul style="list-style-type: none"> • 4.71 Loss of Income • 4.72 Out of Pocket Costs • 4.73 Financial Support
4.8 Domain Summary

4.1 Activities of Daily Living

Four women described how their ADL were markedly affected during treatment. Three women also suffered from other chronic medical conditions which exacerbated the challenges they experienced. One woman described two chronic ailments affecting her ability

to eat and perform simple activities such as bathing or cooking. Combining this condition with the side-effects of chemotherapy it became very difficult for her to maintain her weight or perform basic ADL. She lived alone which resulted in the need to hire someone to assist in meeting her basic needs. Another woman described a profound loss of mobility related to chronic neuropathy, bilateral knee degeneration and a broken foot. Combined with overwhelming treatment-related fatigue challenged her ability to perform basic ADL. However, she described her fortune to have a very supportive husband who helped her with whatever needs she could not meet and also required home care assistance to help her bath. In the third situation, the woman suffered from congestive heart failure, diabetes, sleep apnea and obesity. While on chemotherapy, she experienced severe palmar plantar syndrome which resulted in the sloughing of the skin on the soles of her feet. She was unable to climb the stairs to her bedroom and was forced to purchase a hospital bed that could be situated on the main floor of her home to manage her other chronic ailments. The final situation, a previously healthy, widowed woman living alone described her chemotherapy treatment as highly toxic and talked about basic survival between each of the sessions making ADL very difficult to manage. The remainder of the women were able to adequately manage their basic needs during the course of their treatments. In these situations, instrumental needs were affected.

4.2 Instrumental Activities of Daily Living

Instrumental activities of daily living such as housework, grocery shopping, meal preparation, yard work, banking, laundry, and caring for the house or pets during relocation were described challenges. All the women described the need for assistance from others with these activities although the degree of assistance varied. Eleven women were married and the husband became the primary source of support to manage the instrumental needs of the household. In the

event that the husband was working, family and friends would often step up to help. Women described a variety of activities such friends bringing over meals or family helping with housework, grocery shopping or laundry. Three younger women, age 39, 50, and 56 years, had extensive supportive networks beyond family. One young woman, who was the mother of two young children, described an extensive support system including her parents who moved to her rural community to help her with whatever was needed. While her husband worked, her parents and other extensive supportive networks of people offered their support.

Two of my girlfriends arranged a meal delivery for me over a 12 week period right after the surgery because everyone said I want to bring something by, I want to bring stuff for the kids, we want to bring a meal...arranged every Monday and Wednesday for 12 weeks which is three months to have meals brought here hot and ready. (B3, lines 650-655)

Three women described the journey as very personal and felt uncomfortable receiving help from people outside the family. One woman described a discomfort being in the presence of others and would purposely isolate herself to avoid talking about her cancer therefore her husband became the primary person who attended to her unmet needs in this domain. Nine women were single, widowed, or separated from their spouse and seven of these women lived alone. Three women lived with other family members who assisted with their IADL as required. One woman lived with adult children and a grandchild. Her house was located on a large, un-kept country-like yard. In both interviews, she described receiving minimal support and mostly managed all her instrumental needs herself.

I just did what had to get done, just kind of the bare minimum. My yard as suffered. My, the gardens are gone pretty much. Yeah, I just focused on what had to be done and I got it done. The kids did help somewhat. (C1-2, lines 462-465)

Five women lived alone. A 64 year old woman lived in a small house and received some help with meal preparation from family but mostly hired outside help to assist with her house and yard work. Two highly independent women, aged 66 and 84 years, living in a small apartment were able to manage themselves. Two women, aged 64 and 77 years, were widowed and living on a large acreage in a farm-like setting. Both women had adult children who did not live in close proximity but assisted occasionally. Both these women endured many toxic side effects from treatment but still maintained their household and yard duties independently.

You get very organized because before when the 21st day is up on the 18th, 19th, 20th day you do your cooking, your bill paying, your lawn mowing... grocery shopping, and it was only me so I could stock up and I could do a lot of, when I was feeling better I could do a lot of baking or, or making soup and stuff and that's what you do. (B2, lines 2285-2292)

Five women hired outside help to assist with a variety household duties however, the remainder of the women were able to find someone else to assist with such activities without paying out-of-pocket.

4.3 Provision for Family

Primary care of other family members was not a concern for fourteen women but added an additional dimension of complexity to the experience of six women. The first woman, a young mother of two children, age 7 and 10 years, had an extensive supportive network to assist. She talked about the importance of maintaining an active role as a mother even when she felt unwell. She described being present for important moments such as picking them up from school, preparing lunches together, family meal-time, bedtime stories, and outside activities while maintaining this throughout her illness. Another woman was the legal guardian to two grandchildren, age 7 and 8 years, who were her most important primary concern. Additionally,

she was the primary income earner supporting both her husband and the children. She worried in event that something happened to her, her husband would not be able to provide for the children. She also worried about relocation to the city and who would care for the children. Her sister and husband were able to manage the care of the children while she relocated. However, she was in the process of preparing transfer of legal guardianship to her sister in the event she succumbed to the illness.

Two women were primary caregivers to aging parents. In the first situation, the woman described having to move her mother to an assisted living facility in a city, two hours away from her home while she was very ill from her treatments. She described the isolation she felt not having her mother close by. In the second situation, the woman had an elderly father who lived in an urban setting who she frequently visited. She described him as very demanding requiring daily attention and felt the need not to disclose her illness while maintaining her responsibilities for him.

My dad has dementia and I just felt it would be better that he didn't know so I got the wig just for that purpose so I could go and visit him..at least twice a week and help him with his....at the time he was in assisted living so he needed a few groceries and supplies for his room and stuff and social outings take him to visit friends. (C1, lines 330-334)

Another woman talked about her aging mother with Parkinson's disease, but did not pose additional strain as her sister assumed the primary care during her illness. The final woman had a disabled adult child who lived in a care home 3 hours away. In this situation, she had additional travel demands because she would frequently visit her son.

4.4 Travel

Burden of travel was an important finding in this study. All the women shared their unique experiences with travel while common challenges developed amongst the descriptions. Travel demands, travel safety, road conditions, appointment scheduling, and driving in Winnipeg were described. Additional travel challenges specific to living in the north including NPTP, air, and bus travel were also described. Relocation decisions were also based on travel and each of these topics will be further described.

4.41 Travel demands. Travel demands varied amongst the women in various regions. Women from the SHSS and IEHA had all their treatments in Winnipeg or the local CCP. The women who travelled into the city, including daily for radiation quoted as many as 50 and up to 100 trips to Winnipeg. Two of these women relocated for their radiation and therefore fewer trips were required. The northern women relocated for their radiation and quoted 8 and up to 20 trips to Winnipeg. The women from the PMH had fewer trips to Winnipeg but required many trips to Brandon, quoting 20 and up to 70 trips. These travel demands would be comparable to the women who were from SHSS or IEHR regions travelling to Winnipeg. One woman from PMH lived very close to Brandon and only required 3 trips to Winnipeg for medical reasons. Nonetheless, the women from this region described relief to have most of their treatments in Brandon. Women from all regions expressed frustration with the extensive travel especially when it was only for quick appointments with the specialist or a diagnostic test that was not available in their rural area.

It is frustrating, all these appointments that you have to go to that you're sort of wondering why do I have to go and see two different doctors who do the same thing and I have to drive all the way to

Winnipeg and I have to try to find parking at St. B. and I have, you know for ten minutes. (C5, lines 688-691)

All the women were asked to describe challenging aspects of their experience. Invariable, there were many different answers to this question, but many described travel demands as stressful adding to the complexity of their experience.

4.42 Travel safety. There were occasions when woman had to drive themselves or were required to find someone to drive them for safety reasons. One woman described having to arrange rides based on how she felt each day of her treatments. In this situation, she drove 45 minutes each way for one year of chemotherapy and biologic therapy to her local CCP. It was not easy finding people to drive her for treatments but she refused to drive when she did not feel capable. Another woman described an incident where she was alone when she received the news of her diagnosis and not in a good frame of mind to be driving on the highway.

I was very emotional. I'm not exactly sure how I drove home that day; it was probably not the safest thing for me, nor anyone else on the road. I do remember I was driving behind farm machinery that was going about 50 and I thought that was a good thing, then I could just drive slowly, but I have very little recognition, recollection of, of driving home. (B3, lines 442-446)

Winter driving also created driving safety issues. One woman described traveling daily in the winter in an unreliable vehicle for her radiation. At times she was unsure if she would be stranded on the highway in the event that her car would breakdown. In this situation, the woman did not have anyone who could drive her or a driver service nearby so she was faced with no other option than to drive herself. The remaining women who commuted by land described feeling safe driving on the highway or had others take on the driving responsibilities. Enhancing rural volunteer driving programs was a recommendation suggested by a number of women.

4.43 Road conditions. Women talked about feeling fortunate not to have endured driving due to weather conditions or construction but remained a challenge for some of the women. One woman missed a radiation appointment because of weather but rescheduled. There were other descriptions of women who endured stressful driving conditions. One woman had a many long drives to Winnipeg where winter driving factored in.

The first oncologist we saw in Winnipeg was November and it was miserable out. Dr. XXX was end of February, again that was winter driving and we saw Dr. XXX beginning of March I believe, that was more winter driving which makes it a little more challenging because that one day the roads were so icy. I just kept praying that we were going to make it to my cousins safely. And then it started snowing heavy and the visibility was bad. (B4, lines 2145-2150)

Road construction was also considered. Another woman described a painful ride back to her home community following her surgery due to construction and poor driving conditions. A number of women were worried about the weather because the potential exist that they could miss an appointment or treatment. Weather conditions also affected women who travelled by air from the Northern region which will be described further.

4.44 Appointment scheduling. Most of women talked about accommodating the staff in the radiotherapy department were in scheduling appointments around travel. All the women who relocated to the city for their radiation appointments, with the exception of the northern women, returned home each weekend and were pleased their schedule was adjusted in such a way that they could have a longer weekend and more time at home. Women also described that oncology clinic staff would also be conscious of travel demands and arrange suitable appointment times. A number of women preferred to travel in the morning to avoid rush hour traffic which was mostly accommodated. The women from the north described multiple appointments scheduled to

prevent repeated trips into the city. However, one northern woman described complaining to the staff after making repeated trips and the problem was adverted. Another woman described two trips to see the same physician and the appointments were cancelled. The second appointment was accommodated after much persuasion.

I says "I just drove two hours in the fog and it took us over two hours 'cause it was so foggy." She says "I'm sorry he's canceled his clinic for today." (B4, lines 518-520)

Scheduling appointments for diagnostic tests posed an additional challenge. Most women described many repeated trips for diagnostic tests which were much more challenging to schedule in one day. Considering appointment scheduling around travel was another recommendation described by women.

4.45 Driving in Winnipeg. Four women hired a rural cancer driver service and therefore city driving was not a concern. Other women had family or friends bring them into the city that felt comfortable navigating with maps, GPS devices or were familiar with the city. However, not all women felt comfortable with city driving. One woman described travelling with her husband and they both experienced an ongoing discomfort with city driving but they managed as best they could.

All of the travel we had to do and we weren't familiar with anything in Winnipeg like...you know we weren't familiar with the hospital... it was all a new experience to us. (D2, lines 687-689)

Two women from PMH expressed discomfort with city driving. One woman relocated alone to Winnipeg for her radiotherapy treatment and did the majority of driving herself. She talked about urban driving obstacles such as rush hour traffic and emergency vehicles that she was not used to dealing with. All the women from the north relocated to the city for their radiation and

navigated the city through the mason driver program or taxi service. However, one woman rented a vehicle and was very comfortable with city driving. The second woman had access to a vehicle but often took the bus because of her discomfort navigating the city and fear that she would not make her appointments on time. Parking at the city hospitals also posed a challenge and many women felt better service for patients and families should be considered.

4.46 Northern travel. The women from this region were faced with specific northern travel challenges. They all had financial support for travel through NPTP but unique obstacles with this program occurred. Two women who travelled by air for all of their appointments, described challenges such as cancelled flights or being rerouted extending their trip. One woman had all of her treatments in Winnipeg due to limited access to services in her home community. All of her transportation costs were covered but because of unreliable air travel she would travel well in advance to ensure she would be in the city in time for her appointments. This resulted in her missing additional time at work and further depleting her sick time. Additionally, the doctor made the decision on the mode of travel or escort requirements and completed the necessary paperwork. Two women who lived in the same remote northern community were required to travel by bus and could not have an escort accompany them to the city. In the first situation, the woman suffered from sleep apnea making travel by bus very uncomfortable and therefore used her air miles so she could travel by air. In this situation she felt that HCP should consider other medical conditions when making travel recommendations. In the second situation, the woman was forced to travel alone by bus for all her appointments which resulted in a number very difficult travel days.

Just tired, the bus rides are awful. But no, no, it was just the bus rides its, its uncomfortable, you can't sleep, I remember one trip we never

slept the whole bloody night going down... so you're up like 24 hours by the time you get to Winnipeg and you stay up all day again till you get on the bus that night, so I was up for over 36 hours. (A4, lines 1169-1176)

The final woman from this region had her family drive her to Winnipeg for all of her appointments because of her discomfort with bus travel. In this situation, she was able to claim \$340.00 for travel but the amount did not cover all of her travel expenses. All the women from the north felt that NPTP is essential however challenges still remain.

4.5 Accommodations

Twelve women relocated to an urban center for their radiation therapy. Decisions to relocation or commute were based on a variety of factors such as distance to treatment center, convenience, cost, desire to return home each day, or physical demands of travel. For short stays in the city the women mostly stayed in hotels. However, all the women who relocated for radiation were required to find longer term accommodations. Two women who had radiation in Brandon stayed in a supportive, affordable housing service for people with cancer and is adjacent to the hospital. Both women described this facility as comfortable, clean, quiet and affordable. One of the women also described the social community atmosphere with other cancer survivors as very supportive. In the second situation, the woman described the experience as relaxing, peaceful and enjoyed the time alone. Two women stayed comfortably with family while relocated to Winnipeg and were not required to pay rent but helped out with the cost of groceries. Another woman stayed at a lodge which is adjacent to the treatment center and found this to be a very convenient option as she could walk to her treatment and the cafeteria for her meals. Four women stayed at a supportive, affordable housing service for cancer patients in

Winnipeg. The service was described as comparable to the experience the women had in Brandon.

I think that referring somebody to XXX is one of the best gifts you can give them because it's a community of people who are all going through the same thing and the CancerCare volunteers come right to the door and pick you up and take you to your appointment. (D3-2, lines 274-277)

The experience was not as positive for two women. In the first situation, the woman could not afford relocation costs so stayed with a distant friend. She paid for her groceries and transportation costs in the city which was manageable financially however she described sub-optimal living conditions during her stay in Winnipeg.

I was comfortable, except for the house, the house was not, should be condemned, well he had to sell it now anyway. It was full of mold and I thought I was going to get sick there, full of mold in the bathroom, the ceiling had fallen on him while he was sleeping...And mice, I was petrified most of the time. (A5-2, lines 273-277)

The second woman, an off-reserve indigenous woman, housing was arranged through Keewatin Tribal Council (KTC) Medical Services because her band would not pay for her accommodation costs. While KTC arranged her accommodations she was unsure where she would be staying from day to day and eventually stayed alone in a hotel suite which she described as lonely and stressful. Costs associated with travel and accommodations were also concerns for many of these women which will be described further.

4.6 Employment

Nine women were employed full-time at the time of their diagnosis. Five women decided not to work throughout their treatments and assessed disability or employment insurance income.

Decisions to quit work were individual. One woman, who worked in the retail industry, decided that the added stress of work and demands of her job would be too much to endure.

Two women worked as child care workers and the children were considered in their decision. They described the uncertainty surrounding treatment and time away from work would not be fair to the children. One northern woman was unable to maintain her employment based on travel demands. She talked about profession losses and missing time away from her workplace and if treatment was closer to home she would have been able to maintain professional engagement in her career. Five women continued to work casual or part-time during their illness. Two women had home-based companies and were able to work when they felt well enough. One woman was responsible for all the finance and staffing needs of her company and hired additional staff to assist her because of her inability to function at the same capacity.

I already work 60 to 120 hours a week in my business...how in the world will I run everywhere getting cancer treatments. (D3, lines 421-422)

Another woman who lived close to Brandon ran her own company and maintained part-time status during her chemotherapy and full-time status during her radiation. Additionally, a northern woman worked through chemotherapy and received short-term disability income while relocated for radiation. As the primary income earner she could not afford to take time away from work which would result in lost income or unpaid sick leave.

4.7 Financial Implications

Concerns about finances and costs associated with the diagnosis were discussed in all of the interviews. Loss of income and out-of-pocket costs were the two most significant financial

concerns addressed. In most cases the women were able to manage the financial losses but not without some hardship, incurred debt or outside assistance.

4.71 Loss of income. Loss wages, limits to employment insurance and unpaid sick leave came up in a number of interviews of the employed women. One single woman chose to retire based on stressors related to her job and described the impact of lost income and the need to down-size to a smaller apartment because she used up all her savings.

It cost me a lot because of the fact that I had to leave work and I had no, I didn't have my income coming in anymore, so I, I went through pretty much everything I had in my savings. (C5, lines 893-895)

Additionally, women talked about the need to use their line of credit or incurring credit card debt to pay for their expenses. One woman was forced to do major home renovations because of black mold in her house compromising her health and has not recovered financially from this cost. Another woman accessed short term disability income at 60% of her normal wage in combination to the cost of building a new house prior to her diagnosis causing her additional financial concerns. Additionally, five women were self-employed and did not have any sick leave benefits. Four women did not lose income but had other losses related to hiring additional staff or relying on family to complete the work they were not able to perform. Whereas, the woman who worked as a self-employed child-care worker had a 100 % wage cut during the time she was ill because she was unable to work and did not have sick benefits. Unpaid sick leave was another income loss. One woman returned to work following her radiation but still requires years of travel for hormone injection therapy and cosmetic surgical interventions. She has decided she could no longer manage the ongoing travel and lost time from work and is moving to Winnipeg permanently in a different position.

*I mean financially like me coming down every month, like I lose money. Like I don't pay for my flights or anything like that, it's all covered through NPTP but, but I just, I'm not working so its unpaid sick leave, so every month it's about a week that's unpaid sick leave.
(A2-2, lines 303-306)*

Additionally, the employed husbands would also lose income if they decided to take time away from work. One husband decided to take an early retirement with loss in pay and benefits, to assist his wife during her treatment and travel for radiotherapy. In an alternative situation, the husband took unpaid time to be present for the surgery, chemotherapy treatments and doctor's appointments. The women who were retired were not directly impacted by loss of wage. However, all the women were affected by other out-of-pocket costs unique to the rural experience.

4.72 Out-of-pocket costs. Significant costs associated with illness directly related to living in a rural setting became apparent in most of the interviews. Seven women were able to provide direct quotes of out-of-pocket costs. One southern woman quoted \$10,000 which included over 100 trips to Winnipeg. Two women from the PMH quoted \$7,000 and \$10,000, one woman commuted and the other relocated for radiotherapy. Two women from the IEHA quoted \$5,000 and \$7,000 and commuted for their radiotherapy. Finally, two northern women quoted \$6,000 having travel costs paid for by NPTP, illustrating that the costs were comparable across all the regions of the province. The remainder of the women were not able to estimate their costs but had similar stories based on out-of-pocket expenses they incurred. Medical travel, fuel, accommodations, parking, taxi and meals were the most frequently described costs. One northern woman described additional travel costs because NPTP would not cover her air travel.

I paid for my airplane flight, paid for my taxi, paid for my cancer care or transportation, then my husband would drive me to Winnipeg instead of my flying some of the time, twice, and that's a couple hundred dollars back and forth to Winnipeg. At least a hundred there and a hundred back. (A5-2, lines 318-321)

Other described cost included hiring for household needs such as cleaning or yard work or care for their house or animals while relocated. Many women also described how helpful it was to have cancer drugs covered although other items such as non-cancer drugs, dressing, ointments or other herbal remedies were unrecoverable.

4.73 Financial support. Many stories were shared involving extensions of financial support from their supportive networks. One woman applied to an advocacy group for breast cancer survivors and received over \$1,000 to cover her expenses. Two women described community fundraisers that were organized on their behalf, raising \$3,000 and \$4,000 that were used towards travel and relocation expenses. One woman considered not going for her radiotherapy because of costs associated with relocation and with this support she was able pay her bills at home and eventually completed all her therapies. Other extensions of financial support were described throughout the interviews. One woman had her church and congregation pay for all her driver service costs to Winnipeg at \$25.00 per day. Other women described family or friends assisting with travel or meals and would not accept money in return. Grocery hampers, gift cards and gifts of money were other nominal levels of support that the women received.

4.8 Practical Domain Summary

In summary, the practical domain presented many challenges for the women. Managing ADL when faced with other chronic illness presented unique obstacles. Other daily household challenges or provision for dependent family members also required distinctive intervention.

Some women were highly supported to help them manage whereas others were forced to hire additional help or had no choice but to independently manage. The burden of extensive travel, relocation, employment challenges and financial losses were significant findings in this study. The women had to endure multiple trips to an urban center, hazardous driving conditions, highway construction or navigating an unfamiliar city. All of this added to the burden that they were already experiencing. Accommodating appointment schedules around travel was highly appreciated however limited diagnostic services in rural settings increased the travel demands which further compounded their demanding schedules. Additionally, the northern women had their own unique challenges related to air and bus travel and were forced to relocate for their radiation because of where they live. The other women had the option to commute or relocate for radiation which was personal choice but significantly added to cost or burden of travel. Supportive and affordable accommodation or staying in other comfortable lodging proved to enhance the experience for the relocated women however some were not provided with this opportunity. The financial burden of cancer was apparent and significantly affected the women participating in this study. Employment challenges, lost income and out-of-pocket costs were the primary means attributing to this burden. Although, financial support from friends, family and communities was appreciated, the out-of-pocket cost associated with living rurally was remained noteworthy.

Emotional Domain

The operational definition of this domain, defined by Fitch and colleagues, states that Emotional needs are based on “the need for a sense of comfort, belonging, understanding and reassurance in times of stress and understanding” (Fitch, 2009 pg. 18). The findings in this domain have been categorized according to four broad topic headings including emotional response to illness, releasing emotions, emotional support and family’s emotional response to illness. The following table illustrates the heading summary in the emotional domain.

Table 5: Emotional Domain Summary

5.1 Emotional Response to Illness <ul style="list-style-type: none"> • 5.11 Shock and Disbelief • 5.12 Denial • 5.13 Fear • 5.14 Uncertainty • 5.15 Feeling Anxious • 5.16 Anger • 5.17 Guilt
5.2 Releasing Emotions
5.3 Emotional Support <ul style="list-style-type: none"> • 5.31 Family Support • 5.32 Community Support • 5.33 Health Care Professional Support • 5.34 Peer Support
5.4 Family Response to Illness
5.5 Domain Summary

5.1 Emotional Response to Illness

All the women were asked to describe their feelings and the emotional impact that the diagnosis had on their lives. A wide range of emotions were expressed by the women including feelings of shock and disbelief, denial, fear, uncertainty, anxiety, anger, and guilt.

5.11 Shock and disbelief. Shock and disbelief was one of the first reactions to the diagnosis for seven women. Women described this initial reaction as unbelievable, overwhelming and consuming and found it very difficult to retain any information. One woman ignored the changes to her breast for a number of years and still felt shocked when the diagnosis came.

The women coped with this initial reaction in many different ways. Some of the women isolated themselves from others until they had the time to absorb the news and others found solace from the support of others. One woman described the initial shock of the diagnosis but quickly changed her attitude and remained very optimistic and positive throughout her illness.

At the very beginning though I, I was in shock, then after that I guess I just needed a little time and I guess during that month where there was nothing and I was working and that I guess that's when it just like changed my attitude and say oh no I'm going to beat this. (A1-2, lines 763-766)

A woman from the IEHA expected the positive biopsy result but felt shocked when she was told she required all the treatment modalities. Another woman described the disbelief as an ongoing emotion at various points of time in the journey “*sometimes you feel like it can't be happening....that this can't be real*” (D1, lines 399-400). She described disbelief when she was in hospital for her surgery, lost her hair, started radiation and throughout testing. At the time of the interview she stated that she still struggles with this difficult emotion. The remainder of the women felt certain that the biopsy results would be positive prior to receiving their diagnosis and did not experience this reaction.

5.12 Denial. Denial was described by three women early on in the diagnosis. One woman described her denial where she believed they told the wrong person the diagnosis and isolated

herself from her family and community until such time she could absorb the news herself. Another woman described initial shock of receiving the diagnosis which quickly turned into denial. She was so overwhelmed and devastated with the diagnosis and continued to have a difficult time coping throughout her journey and at the time of her interview.

I buried my head in the sand and I didn't want to know anything about breast cancer. I just kept saying "I'll get the lump removed and everything will be okay. It won't be cancer, there's been a mistake, it's just, it's just a mistake and everything will be okay." (B4, lines 320-321 and 381-383)

She expressed feeling upset that her family doctor did not offer counselling service or support at initial diagnosis to help her through these difficult emotions. At the time of the interview she was seeking emotional support a navigator as her denial turned into fear.

5.13 Fear. Fear was one of the most commonly described emotions expressed by the women. The women used descriptive terms such scared, terrified, frightened, petrified, and afraid. Waiting for initial test results was described as a very fearful time. One woman waited 5 months from initial abnormal mammogram to the time when she received her results. She subsequently was required to wait an additional month for surgery and described feeling terrified, fearful and had a difficult time coping. Once the results were revealed an urgency to have surgery for fear that the cancer would continue to grow was described by many women. In this situation the woman fear was escalated based on a significant family history of cancer including her sibling who was in the palliative stages of advanced cancer.

I want it dealt with right away. Because the, in my mind I was convinced that every day that something didn't happen, no surgery, no treatment, every day the cancer would just grow and grow. (C4, lines 320-322)

With the new diagnosis, fear of mortality was also revealed. Fear of leaving children or family members behind. Fear of reoccurrence, cancer spreading or treatments not working were expressed. Women described ongoing fear of reoccurrence that would increase in intensity leading up to medical checkups and diagnostic tests. Nine women described ongoing fear related to the threat of reoccurrence which remained throughout treatment and in the follow-up stages of illness. Facing mortality will be described further in the spiritual domain discussion.

Additionally, fear of surgery and other invasive procedures were also described. Two women talked about challenges with accessing their CVL which heightened their fears. One woman travel 45 minutes to her CCP with her fears escalating during the drive for fear they would have trouble with access. Another woman from a northern region of the province was afraid of anything invasive and each trip for cancer care made her feel “petrified”. Many women talked about fear of surgical procedures. One woman was very afraid prior to her bilateral mastectomy based on other co-morbid conditions which increased her surgical risk. Another woman talked about feeling very afraid to have her port-a-catheter inserted.

Many other fears were also revealed including fear of chemotherapy and radiation, side effects of treatments, receiving results and doctor appointments. One woman was extremely ill during her chemotherapy treatments and was very afraid to receive each treatment as her symptoms escalated with each cycle. Alternatively, she was also afraid to stop treatment for fear that the disease would reoccur.

I think I was too scared to quit. I was too scared not to take it just in case it came back. And everybody tells me that when it comes back it like comes back with a vengeance and then you're scared, then you're really scared. (B2-2, lines 82-84)

Additionally, these heightened fears would often cloud the ability for the women to retain any information that they were receiving about their diagnosis creating additional uncertainty.

Considering the unpredictable nature of the treatments and challenges with retaining information, uncertainty became another emotion revealed as the interviews unfolded.

5.14 Uncertainty. Uncertainty heightened the fear that many of the women were experiencing. The women were faced with making decisions surrounding treatment while feeling uncertain about what to expect. Fear of the unknown was described by many women throughout the journey. Women also expressed feeling uncertain about proceeding with treatment but feared for their lives if they did not proceed. Uncertainty surrounding chemotherapy and potential side-effects was also a common concern for many women.

I remember being very scared and very nervous that first one, you know not knowing kind of what to expect. I was really scared about throwing up and being nauseous all the time. (B5, lines 735-737)

Additionally, uncertainty surrounding radiation also existed. One woman talked about considering not having radiation because of the uncertainty surrounding long-term side-effects but eventually completed the therapy after much deliberation. Some women talked about the need for information would help them cope with their feelings of uncertainty whereas others found the information would escalate their fears.

5.15 Feeling anxious. As fears and uncertainty escalated, heightened feelings of anxiety would often follow. Women talked about feeling anxious prior to appointments. Others talked about feeling anxious when receiving test results. One woman received an explanation of her pathology results and treatment plan over the phone which provoked an anxiety attack resulting in intervention.

I needed chemo, I needed radiation, I needed to take this pill, I needed Herceptin. She told me about the grade of the tumour, the stage of the tumour and I just about lost it, I saw black, I kid you not, I was hyperventilating on the phone. And she talked me out of it...I had to put my head back and everything was just going black on me 'cause I didn't want to have chemo. (B4, lines 554-560)

This heightened anxiety lasted well into the night for this particular woman while her husband was ready to take her into the emergency for intervention. Other women talked about waiting to start treatment as anxiety-provoking because of the anticipation and uncertainty surrounding the treatment. Women also talked about feeling anxious about the health of their daughters for fear they would develop breast cancer in their future. Another woman felt fearful that her daughter would grow up without a mother which caused her a great deal of anxiety.

That was, it wasn't for me, it wasn't about pain or suffering or anything, it was just our daughter is 10, it's the most tenuous time for her. She needs a mother, so that for me was yeah it was, it caused a lot of anxiety for me. (B3, lines 553-555)

Feelings of anxiety were also heightened prior to invasive procedure or tests. A northern woman will require a Zoladex injection monthly for 10 years post breast cancer therapy and feels anxious prior to each appointment because of her fear of needles. The women experienced many anxiety-provoking events throughout the journey based on their own unique and particular fears.

5.16 Anger. Many expressions of anger were illustrated in the interviews. One northern woman described many sources of anger throughout her experience. Some of her expressions included feeling anger towards the diagnosis, loss of personal control, having to hide her fears from others, and the never-ending journey of cancer. She talked about feeling anger over the lack of cancer services in her home community, travel demands and being alone while she was

relocated in Winnipeg. One of her recommendations for improvement in services was increasing diagnostic services and specialist site visits in rural communities. Women also talked about feeling angry towards the quality of treatment that they received and with particular members of the health care team. One woman described four incidents where she did not feel she was treated properly. Although she had many positive experiences, the negative experiences remained significant to her. She provided a very detailed description of an unnecessary painful mammogram from the rural travelling program. She also described three separate incidents in urban treatment centers where she felt disregarded and disrespected by HCP which deeply impacted her.

Cancer is already a big sock in the head....and you feel upset and you feel betrayed and I felt upset I felt angry I felt betrayed. (D3, lines 527-528)

Other women described incidents where they felt angry about the quality of treatment they received, two of which occurred in Brandon. In the first situation, a woman described care from an inattentive nurse during a post-surgical complication. She was very afraid during the experience which later turned into anger towards the nurse. In the second situation, the woman described a long wait period for her initial biopsy results when she was already feeling scared and anxious.

They are going to tell me that I have Cancer and I have to wait here 2 hours. I was kind of angry about that. (B1, lines 210-211)

Three other women talked about feeling angry towards Winnipeg HCP. Two situations involved sub-optimal in-patient nursing care and another involved an urban surgeon. In the later situation, the youngest woman described feeling “attacked” by the surgeon when he told her the results of her biopsy and felt angry on how it was handled. In a fourth situation, a woman described feeling

a lack of compassion from a medical oncologist when she was feeling overwhelmed, scared, and vulnerable. In this situation, she decided to change oncologists from the advice of a nurse when she was feeling very angry with how she was treated. Women also expressed anger towards quality of care received in rural settings. Three women described challenges with inexperienced family doctors or lack of family doctors as a source of anger and stress. Another woman described anger towards a rural pharmacist who made an error in dispensing her Tamoxifen prescription.

And she called me back and she said yeah, you were supposed to be on 20 milligrams and they misinterpreted my prescription for this whole last year. So I was just getting to a place in my life, a happy place where I wasn't consumed with cancer and I hear this. So I was a little angry and upset. (B1, lines 1039-1045)

Women also expressed anger toward other hospital staff. One woman described anger towards the inexperienced emergency HCP in regards to her drain removal. Another woman received chemotherapy both in Winnipeg and local CCP and when asked to compare the experiences she said the nurses did not follow the same procedures as the nurses in Winnipeg and felt “disgusted” with her care in the rural setting. At that point she asked to have her care transferred back to Winnipeg for the remainder of her therapy but was told they would be unable to accommodate her request once she moved to the rural site.

5.17 Guilt. Women spoke about feeling guilty in a range of circumstances. Two women talked about feeling guilty that they might pass the cancer onto their daughters and felt worried about their future. Another woman talked about how she was consumed with guilt related to the diagnosis and purposely isolated herself from the community until she could overcome these feelings.

Part of me felt, this will sound silly but guilty or embarrassed, like what did I do to deserve this... you know is it drinking too many diet Pepsi's...I'm not a drinker... I'm not a smoker...I don't have any of the typical risk factors other than being a woman with breasts. I felt guilty and I felt ashamed and so we told our families but we asked our families not to tell anyone. (B3, lines 620-625)

Another woman felt guilty bypassing the rural CCP nurses when she wanted to speak to the experts in Winnipeg with her distressing symptoms. She was worried that she may offend the community nurses in some way. In a final situation, a woman described feeling guilty for being alive while others around her were dying of the disease. Women also talked about feeling guilty wasting the HCP time or causing extra strain on other family members.

5.2 Releasing Emotions

As the interviews unfolded it became clear that it was very important for the women to find ways to express the complex emotions they were experiencing. Some women talked about feeling so overwhelmed that had a difficult time to keep it all together and felt deeply consumed with emotions.

I remember walking out of his office right over to the hospital and getting into the little cubicle for an EKG and I just, I was just sobbing...I remember them calling me in to get that EKG and I was, I couldn't stop sobbing and she just, you know she was really good, she just kept telling me to relax and to take a deep breath. (B4, lines 297-300)

Others talked about spending time alone just to be able to release their emotions that were consumed with. A young mother who did not want to her children to see her in a vulnerable state would take time to herself when her children were at school to cry so she could feel some relief from the sadness. She talked about having good and bad days and releasing emotions would give her the strength to tackle a new day. Releasing emotions through crying was talked about by

many of the women. They described times when they could not control their emotions and crying became an important release at times when they were feeling the most vulnerable. The women talked about many other strategies they used to keep their mind off the diagnosis or distract them from the complex emotions they were experiencing. Some women used art therapy, music, yoga, meditation, reading or gardening to help them cope. Whereas other felt comfort in working, going for walks, spending time with family or journaling. These coping mechanisms will be further described under the psychological domain descriptions.

5.3 Emotional Support

The emotional response to the illness was unique to each individual situation. The degree of emotions varied and changed at any given time depending on the situation. The women worked through their feelings in their own way and in their own time. Not all women experienced the wide range of emotions described in the previous section. Some women had profound emotions that they had to work through whereas others were not as deeply consumed. However, the women would often utilize the support from others to help them deal with the complex and vast scope of emotions they endured. Family, community, professional and peer support was utilized by all the women to various degrees and will be discussed further.

5.31 Family support. Family support was one of the most critical ways that the women used to help them meet their emotional needs. Primary supportive roles included their husband, children, parents, siblings or other extended family members. The women utilized family members to release and validate the emotions that they were experiencing. One woman was emotionally devastated by the news of her diagnosis and found comfort from the support of her husband by being held and crying. She also felt a significant bond with a sibling who was also had lived experience with cancer and currently in the palliative stage of illness. Another woman

was very afraid for her grandchildren if she were to die from this illness and found it very helpful to talk about her fears with her sister.

But my sister was the only one that I could talk to about, the biggest fear I had is what's going to happen to my boys if... it was always that if.... And.... she never.... she never broke down in front of me, she never tried to change my mind about things except once, and I never thought about her needing to talk to somebody too 'cause she just kept it in and she just let me talk. (A4, lines 412-416)

Additionally, family members attending doctor appointments or chemotherapy sessions would also alleviate some of fears or feelings of anxiety that the women were experiencing. Having someone with them to keep them distracted, hold their hand or be a supportive presence was comforting. It also proved to be helpful to have family members present to help them process the complex information they were receiving when they were unable to retain the information themselves. These early appointments with the specialist proved to be extremely difficult and a comforting family presence was very important. Many women talked about the overwhelming support they received from family but the degree and nature of support varied dependent on each social situation. However, each of the women found someone they could lean on when they were feeling vulnerable and in need of a supportive presence.

5.32 Community Support. Community support was another means to help the women meet their emotional needs. Support from community members, neighbours, co-workers or friends was valued but played a lesser role in helping the women with the complex emotions they were experiencing. Women talked about how these relationships helped with some of their instrumental needs such as providing a meal or financial support for travel. These contributions from community members eased some of the burden the women were feeling and therefore helped them cope emotionally. Spiritual supports from congregation members or religious

figures were also a source of emotional support for the women. These supports will be further described in the spiritual domain discussion.

5.33 Professional Support. It became clear as the interviews unfolded the valued role of the HCP in providing emotional support for the women. Doctors were mostly described as providing informational support. However, some of the long-standing rural family doctors did provide emotional support but not to the same degree as nursing. Oncology nurses in Winnipeg supported the women when they had their initial appointment but the relationship with the nursing in the rural CCP was significantly different. The majority of the women talked about the impact of the rural nursing care they received. Their care was described as personal and intimate and they felt cared for and emotionally supported by the nurses. Many of the women talked about being able to share their feelings and concerns and found comfort in having someone to talk to. A number of women even talked about how difficult it was to not have the frequent contact and emotional support from the nurses once their treatments were completed.

Once you're done all your treatments you feel like you've been cut right off. That's the way I felt after I had chemo and radiation and then no one was kind of taking care of you anymore.... Almost like a grieving process. Because all these people are taking care of you and they were hovering over you and they cared that you weren't feeling good and all that and then all of a sudden they're not there anymore kind of thing, so that was hard. (B1, lines 1216-1220)

The women who utilized the nurse navigators also described the supportive role that they had in their experience. Other HCP such as social workers and counsellors were utilized by only a few select women but were also positively viewed.

5.34 Peer Support. Twelve women described the role of emotional support they received talking with other cancer survivors or peers. Having the ability to vent and validate their feeling

or concerns proved to be very helpful. A number of women talked with family, friends or other community members who have gone through similar experiences. Others found comfort in talking with others in the rural CCP or in their relocation housing facilities. Two women talked about the role of volunteer drivers as a source of emotional support. These volunteers are often people who have been affected by a cancer experience which would often result in sharing experiences. One woman attended an on-line cancer chat group which she found very helpful. Another woman continued to attend a monthly support group for cancer survivors located in her home community and found that validating and normalizing her experience to be very comforting. She plans to continue with this support group as she wants to give back to others what she has gained from this experience. Only one woman utilized the mentorship peer-support program at WCCH. This woman was linked to a person in her region and developed a deep bond with this individual.

They match you up with somebody whose, has the same, similar type of breast cancer, similar type of experiences and treatments, that type of thing. And so she, she was a lifeline for me as well, you know somebody that I could call and, and say you know, okay so it's the first time I really felt sick. (C4, lines 706-710)

Talking with others who have similar experiences would help the women feel less anxious and more hopeful about outcomes while validating their emotions. Although, some of the women talked about the need to have quiet private time, receiving emotional support from others proved one of the most important means to meet the emotional needs of the women. Many women felt the services such as the peer support program were underutilized and advertized in rural settings.

5.4 Family's Emotional Response to Illness

It became clear throughout the interviews that family was also deeply affected emotionally by the diagnosis. Eleven women were married and living with their spouse. Eight of the men were described as strong, supportive and positive. They often provided the women with the emotional support they required yet would often keep many of their own concerns or fears to themselves. However, it was difficult to interpret the emotional reactions of these men from the interviews other than a primary supportive role. The final three married women did not share the same experience. One woman did not talk about the impact of the diagnosis on her spouse. In this situation, he provided some instrumental support and her sister was her primary emotional support person. Another woman talked about how her husband became physically ill as a result of her diagnosis and was unable to support her emotionally. He would not talk to her about her cancer, attend her appointments, or visit her when she relocated for her radiotherapy. The third woman described her husband as very emotional about her diagnosis experiencing many similar highs and lows as she had.

I remember one day I was having a good day and he was having a bad day, and I remember just walking by him and he just, I remember he just grabbed me and he just brought me into his shoulders and he just, he broke down. (B4, lines 583-586)

The women who had young children or grandchildren in their lives described concern for the children's emotional well-being as a poignant aspect of their experience. The women attempted to protect the children by shielding them from certain information. One woman who was the primary guardian of two grandchildren did not tell them about her diagnosis so they would not be afraid. Another young mother talked about the emotional challenge of protecting her children from her true emotions. Many of the women had adult children who were also deeply affected by the diagnosis. A wide range of emotions were described including anger, shock, denial, and fear.

Some adult children had a difficult time talking about the illness whereas others were very attentive. Many of the women described their children to be very fearful that they may lose their mother. The adult children of the widowed women had the additional fear of potentially losing another parent. One woman described her adult daughter to be in denial over the diagnosis which caused a breakdown in communication.

She lost her dad and didn't want to lose another parent, so it was like, no you don't have cancer, no this isn't happening, sort of like, so it was kind of tougher, tougher decision try and talk to, so we kind of like skirted around the issue all the time. (B2, lines 152-155)

It was often the women who would have to take on the role of parent to help their children come to terms with their diagnosis when they were already feeling vulnerable themselves. Siblings and parents were also mentioned by many of the women but the emotional impact of the diagnosis on these family members was not thoroughly described in the interviews.

5.5 Emotional Domain Summary

In summary, the women experienced many complex emotions throughout the course of their journey. Shock, disbelief, denial, fear, uncertainty, feelings of anxiety, anger, and guilt were described in the interviews. Some of the complex emotions the women faced were accelerated by the rural experience. Escalated emotions around travel, relocation, challenges with care providers, additional costs, and employment complicated the experience. The women were able to find ways to release many of their emotions they experienced and often found solace in family, community, HCP and other cancer survivors to meet their needs. Moreover, the impact of close knit communities and highly personalized care in the rural CCP also helped facilitate the complex needs identified in this domain. Family response to illness was briefly described but not thoroughly explored in this study.

Psychological Domain

The operational definition of this domain, defined by Fitch and colleagues, states that Psychological needs are based on “needs related to the ability to cope with the illness experience and consequences, including the need for optimal personal control and the need to experience positive self-esteem” (Fitch, 2009 pg. 19). The findings in this domain have been categorized according to three broad topic headings including unmet psychological needs, gaining personal control and wellbeing and personal attributes. The following table illustrates the heading summary in the psychological domain.

Table 6: Psychological Domain Summary

6.1 Unmet Psychological Needs <ul style="list-style-type: none"> • 6.11 Loss of Control • 6.12 Altered Body Image • 6.13 Decreased Self Esteem
6.2 Gaining Personal Control <ul style="list-style-type: none"> • 6.21 Changing Perspective • 6.22 Looking for Opportunities • 6.23 Distraction • 6.24 Maintaining Wellness • 6.25 One Day at a Time
6.3 Personal Attributes <ul style="list-style-type: none"> • 6.31 Resilience • 6.32 Self-Reliance • 6.33 Optimism
6.4 Domain Summary

6.1 Unmet Psychological Needs

Many unmet needs have been featured in other domain discussions which had an impact on the psychological wellbeing of the women. However, unmet needs that require further description will be highlighted including loss of control, altered body image and decrease self-esteem.

6.11 Loss of control. The women talked about many aspects of their cancer journey that were beyond their control. They described having no control over the cancer itself. One woman from the north felt “terrified” through most of her treatments. She was also alone during the diagnostic phase of illness when she felt the most vulnerable. She talked about feeling forced into a situation that she did not have any control over.

I think that I zoned out half the time when I was going looking for the places that I had to be in the hospital and it was something like, I felt like as an experience in my life I feel like it was something that I was forced to do and somebody was just pushing me to try to get me off the cliff, that's what it felt like. (A5, lines 889-892)

Many of the women struggled with the challenging concept of having chemotherapy or radiotherapy once the cancer was surgically removed. They often wondered why they couldn't just “cut out the cancer” or “remove the lump” and it would be over with. The women mostly felt they had input into the treatment decisions but had no option but to proceed with further therapies. They also had little control over the outcome or potential side-effects they may experience. Four women had family members who also struggled with the concept of having adjuvant therapy which added additional stress for the affected woman. The oldest woman who participated in the study, her daughter was very upset about her mother going for chemotherapy resulting in a delay in starting therapy until she was willing to accept that her mother required treatment. Four women talked about possibility of not having specific treatments but the alternative was not something that they would be prepared for and therefore had little control over the treatment decisions.

It sucked...if I don't, I'm doomed. If I take it I know I'm going to be sick. I don't know, you don't know what to do. You know you, you know that it's, if it's going to be lifesaving you have to take it. I didn't want to take the chance of not taking it. (B2, lines 1023-1026)

The need to relocate or travel to where the specialized treatment was located was also beyond their control. This proved to be a difficult aspect of the journey which had a profound impact for the women. They also talked about loss of control over aspects of their lives that they would normally have control over such as work or other household needs. The need to ask for help with aspects of the lives resulted in a further loss of independence and control. Therefore, they were not only dealing with the physical and emotional effects of cancer, but now they were more dependent on others for simple daily needs. Many women talked about the need to find ways to gain control over various aspects of their lives which will be described later.

6.12 Altered body image. Body image challenges affected the women in a variety of ways. Only two women, 84 and 50 years, were comfortable with the changes they experienced. They both had a lumpectomy and were not bothered by their hair loss or other changes to their bodies. Five women had their breast/s removed with no reconstruction. One woman opted to have an implant inserted at the time of the surgery but chose to not look at the site of her breast because she found it difficult to look at. Another woman who had a bilateral mastectomy feels unhappy with her appearance. In this situation, she decided against reconstruction because of her increased surgical risk related to her chronic medical conditions. She talked about her loss of breasts being disproportionate to her body size and also feels uncomfortable with the surgical skin flaps under her arms. Five women had reconstruction following the removal of their breast/s. Only one woman feels uncomfortable with her reconstruction and regrets her decision mostly related to the discomfort and scarring from her abdominal flaps. At this point in time she was unsure if she would proceed with further cosmetic surgery and will make that decision at a later date. One woman was very concerned about the potential change in body image related to lymphedema and remains very cautious to prevent this from occurring. All the women

experienced complete alopecia and for ten women this had a significant impact on their body image. Women talked about hating the way they looked and avoided looking in the mirror.

I couldn't look at myself in the mirror, I just couldn't face, I looked like a man and I just thought I was so ugly and I hardly would let my husband look at me. And I didn't want a wig, I tried on tons of wigs and they all looked stupid on me. (C3, lines 255-258)

Others felt uncomfortable going out in public places or felt it was a constant reminder of the disease. Two women continued to be plagued with this ongoing challenge as their hair did not fully returned post-treatment. Weight gain was also another symptom described by three women who found it to be quite upsetting. The two youngest women who were pre-menopausal at the time of their diagnosis were now dealing with hormone-induced menopausal symptoms unfamiliar to them. Additionally, these women also expressed concerns related to their sexuality. The first woman talked about the importance of an intimate relationship with her husband. She was worried not only with the surgical changes to her body but also menopause-induced sexual transitions.

You know I'm 39 and I'm not 80 and you know having an intimate relationship with my husband's pretty important. So to go and have the menopausal symptoms affect our intimate relationship, that's hard at 39 and it's probably hard no matter what age you are but not when you're not you know planning on that. (B3, lines 2339-2343)

The other woman was in a casual intimate relationship but felt the scarring from her multiple reconstruction and cosmetic surgeries would always become a part of any future relationships that she may become involved in. The remainder of the women were either in menopause or post-menopause and were not as directly affected by these symptoms. None of the remaining women talked about concerns regarding their sexuality.

6.13 Decreased self-esteem. As women experienced changes in their body image it also appeared to affect their self-image. Body-image and more specifically hair loss appeared to be closely linked to self-esteem and the way they felt about themselves. Seven women talked about completely isolating themselves from public places such as shopping or restaurants because of their discomfort with the way they looked. A number of these women would not feel comfortable with others seeing them without some form of head covering. One woman talked about dressing herself up with “dangly earrings and scarves” to try to turn the attention away from her baldness. Other women talked about feeling embarrassed by the diagnosis and felt people would stare at them. One woman described avoiding public places including her church because she felt ashamed of the diagnosis. In this situation the woman finally was able to attend a church service but described the experience as “highly emotional”. Another woman felt embarrassed by her diagnosis which attributed to years of smoking and assumed people would judge her for it.

I avoided going out sometimes, but it, like I said I went to the wedding and I still, yeah you feel different, you feel, some people feel really bad for you and so it's sort of like an embarrassing ordeal that you're sick with cancer and that maybe that you did something wrong. (A5, lines 1929-1932)

Changes in body-image and effects on self-esteem were difficult aspects of the journey that the women worked through in their own unique way. Other unmet needs described in the different domains discussions also affected the women from an emotional and psychological perspective and required specific strategies to help them cope with the illness experience and regain some control of their lives.

6.2 Gaining Personal Control and Wellbeing

Coping with loss of control, altered body-image and decrease self-esteem or other unmet needs resulted in the need to find new ways to cope to improve wellbeing and quality of life. Each of the women uniquely coped with the illness experience and complex emotions. Accessing new information or resources was one strategy utilized. Another strategy previously described included reaching out to others for support as a primary means of coping. However, other strategies also proved to be very helpful. Changing perspective of illness, looking for opportunities, distractions, maintaining wellness, and a one-day-at a time approach are some additional strategies the women utilized.

6.21 Changing perspective of illness. The women were in a position where they could not change elements of the illness that were beyond their control. Therefore, many of them chose to change the way they viewed the illness. Two women chose to avoid thinking about aspects of their journey that were beyond their control and focus on other aspects of their lives. Both of these women talked about going through the experience in a “daze”. Other women talked about “forging ahead” and not dwelling on what was beyond their control. One woman talked about regaining personal control by forcing herself to continue to keep her life as “normal as possible”. She would purposely seek people out and would not avoid talking about her illness even if others were uncomfortable with it otherwise she felt that the cancer would win.

I'm not going to stop living my life because I've got cancer, cancer is not going to do that to me, I will not let it do that to me. (C4, lines 1701-1702)

Another woman described how she let go of emotions she could not control. In one example she described how frustrating it was to wait for hours in the waiting room for appointments. She felt

that accepting the emotions she was feeling allowed her to move on and not dwell on it. Other women talked about how they could not change the diagnosis so they had no choice but to move through the process therefore choose to be as strong as possible. Changing the way the women viewed the illness or altering their perspective provided the women with an alternative way to cope with the experience in a more positive way.

6.22 Looking for opportunities. Women talked about opportunities that opened up to them because of their cancer experience. The youngest women frequently talked throughout her interviews about opportunities that came from her experience. She was able to travel more, established new and important relationships in her life and developed a deeper appreciation and respect for self. She was also forced to ultimately move to Winnipeg because relocation and travel demands were affecting her professionally. She was able to find a new and interesting job in Winnipeg and described this as a new chapter in her life. Seeking opportunities and not dwelling on the challenging aspects of the experience was her way to cope throughout her entire journey.

I mean just being able to be in a situation like that and try to just take advantage of the opportunities that can come with it and not, you know not dwelling on it or like allowing yourself to, but not allowing that to be predominantly how to respond to it. (A2-2, lines 2038-2042)

Another woman talked about aspects of the journey that she really enjoyed. She described herself as a very social person and found opportunities in many relationships she had made while having her treatments in the CCP. She talked about feeling so cared for and “loved” by others which will change the way she will approach relationships into her future. Additional quotes such as “stop and smell the roses”, “make more memories”, “build relationships”, “second chances”,

“slow down and enjoy life” or “live for the moment” were other expressions which illustrated potential new opportunities.

6.23 Distractions. Distractions were found to be an effective strategy to help the women keep their mind off unpleasant thoughts and helped them feel better about themselves. One woman utilized meditation and yoga as a way to help her relax. Another woman attended art therapy classes at CCMB to keep her busy. Other activities were also described such as music, walking, gardening, or reading as a few examples. Additionally, women also talked about how pets were also a very comforting distraction. One woman who lived alone and recently widowed felt she would not have been unable to deal with her loneliness at times when she was feeling the most vulnerable without the company of her cats. Another woman brought her small dog to her workplace and mentioned he was a comforting companion. Work was also another important distraction for the women who maintained employment status. Two women talked about the boredom of illness and work kept their minds occupied. Another woman found work to be highly therapeutic and distracted her from the deep emotions she was experiencing.

I love bookwork most people don't but I just found it really calming to me that's something that...my niece has a business and she said "I don't know how you can stand it" but it just does calms me down, I don't know why. (D2, lines 148-151)

Six women found distractions during chemotherapy to be very comforting and having family or friends attend their sessions helpful. Children also proved to be a good distraction for many. One single woman was living with her daughter and her 3 year old grand-daughter who would brighten her day. Another woman was very lonely and struggled deeply with relocation to the city for her radiotherapy. She deeply missed her grandchildren and was ready to leave the city without completing her therapy. She talked about how she tried to keep herself as busy as

possible to help her cope. The majority of the women found distractions as an effective coping strategy to help keep their minds occupied. One woman described night time as a very difficult time for her. She found she was easily distracted during her busy day with her children and others around her but at night she would be consumed with other thoughts. Distractions proved to be an effective short-term strategy to help the women avoid or suppress the negative emotions that they were feeling which ultimately improved their psychological wellbeing.

6.24 Maintaining wellness. Another means of gaining control back into their lives included staying as healthy and well as possible. Women talked about exercising more or eating healthy. One woman purposely maintained her garden during the summer so she would continue to eat fresh vegetables on a regular basis. The young mother with two small children was surrounded by supportive friends and family who brought them regular healthy meals. This was very important to her, not only for her own wellness but also for her family. Another woman talked about how she started walking 5 miles every day either outside or on her treadmill which was not her usual routine pre-diagnosis. One woman who struggled with her weight has made a choice to adopt a healthy lifestyle of diet and exercise. At the time of the second interview she had started to regain some of her energy post-treatment and is now exercising on a daily basis.

My choice is fit, strong and healthy, that's my deal and I'm like full-time into this fit, strong and healthy, I need to exercise every day in some way. (D3-2, lines 1069-1071)

Another woman was very focused on natural dietary intervention. She had a list of foods that she would avoid such as sugar or soybean because she felt they would “feed cancer” or “mimic estrogen”. She found this information off the internet and felt strongly this alternative dietary intervention would keep her healthy. A number of women talked how important it would have

been to have dietary teaching and intervention during their experience. Maintaining wellness not only made the women feel better and improve their self-esteem it also help them regain some of their strength post-therapy.

6.25 One-day-at-a-time. For many women, a-one-day-at-a-time approach to their illness proved to be quite an effective coping strategy. It became more manageable to process the experience in this step-by-step fashion. Women talked about focusing on what had to be done today and not focus on the uncertainty surrounding each treatment modality or illness outcome. One woman talked about how this approach helped her stay more grounded. Another woman described over 60 trips to Winnipeg resulting in over 10,000 kilometers of travel during her year of therapy. While the travel demands were overwhelming for her and her husband they decided that they had to focus on what they had to do in any given moment.

I guess you just cope the best you can...Like you almost kind of get into this mode where well I have to do this, this is what I'm focusing on right now, this is what I have to do, like going back and forth every day, that was what you had to do. (D2-2, lines 896-901)

Other women talked on staying focused on task. It not only helped them cope with emotions or loss of control over the illness but it also helped them process the complex information that was being presented to them in a step by step format which was found it more manageable and less overwhelming.

6.3 Personal Attributes

Many of the women shared similar and distinguishing attributes that were found to be quite effective coping strategies to help regain a sense of control and self-esteem. Resilience, self-reliance, and optimism will be described further.

6.31 Resilience. For the majority of the women resiliency appeared to be an attribute they demonstrated which guided them throughout their illness experience. The adversity and ongoing challenges that they faced were often described as complex and difficult. Despite this, the women had the ability to forge ahead and face each challenge as it was presented. A number of the women talked about feeling surprised as to how strong they were when they were given this opportunity to reflect back on their experience through the interview process. One woman never really let herself become upset during her experience. Although, she had a very supportive family, she also faced many of her challenges alone including her early appointments when she was first diagnosed and relocation for radiation. In this situation, the woman had faced other challenges in her life including a separation from her husband and her daughter's teenage pregnancy and talked about facing this experience in much the same way.

I guess I'm strong, I can, I've dealt with it, conquered it, yeah. And life goes on. (A3-2, lines 629-630)

Another woman talked about how she worried about her family more than herself. Although, she had weak moments throughout her experience she described herself as having an inner strength to keep everyone together including her adult children who were struggling with her illness. Many of the women demonstrated a mental toughness that was illustrated in a number of ways. Women talked about not wanting others to feel sorry for them and tackling their challenges head on. One woman who lived alone was very strong and resilient throughout her journey. She was extremely ill during her chemotherapy, traveled independently for many of her appointments including radiation and continued to live an independent life in her home on a large acreage. Other women described themselves as “fighters”, “optimists”, “practical”, “positive” or “strong” while utilizing strategies such as “take the bull by the horn”, “deal with it”, “tough it out”, “go

through the process” or “on to the next thing”. Resiliency appeared to be an approach that helped these women adjust and positively adapt to the illness experience.

6.32 Self-reliance. Self-reliance was another approach utilized in a variety of ways by most of the women at difference points of time in the journey. Three women were highly supported by family or friends but were forced to become more independent when they relocated to the city alone. Three other women who were also highly supported throughout their illness but were selective about the aspects of their lives that they wanted to maintain independently such as work or raising family. The women that lived alone all demonstrated self-reliance in many aspects of the lives. One widowed woman who lived alone described her independence as very important. She felt challenged when she lost aspects of her independence. In this situation, she commuted to Winnipeg for her chemotherapy utilizing volunteer driver support. She then relocated to her son’s house for her radiation on the advice of her doctor resulting in a loss of independence. When she was finally able to return home and drive herself for the remainder of her Herceptin treatments she described feeling “liberated”.

I don't like to depend on other people, I like my independence, I like to be able to do things myself. (C2-2, lines 466-468)

Another woman who lived alone maintained as much independence as possible. She also suffered from many other chronic conditions and therefore was forced to hire people to look after her house and yard. She talked about how important it was for her to maintain as much independence as possible especially in regards to making her own decisions regarding treatment choices and plans for relocation. In this situation, she did not feel supported by family and felt proud that she was able to be as self-reliant as possible and does not regret any decisions she made. For the remainder of the women maintaining some degree of independence was very

important. Some women were forced to be independent because they had little outside support but for others it became a personal choice and helped them regain some control over the illness experience.

6.33 Optimism. Maintaining a positive and optimistic attitude was a very important strategy to help the women cope. One woman talked about how her positive attitude helped her get through many of her challenges and gave her the energy to fight. This woman was highly supported by friends and family but described her positive attitude as one of the most important strategies she utilized throughout her experience.

I find too that like I find that if you get depressed and stuff it's going to make you sicker, I find that, that's, and it is true you know....And you have a positive attitude and stay happy and whatever, then yeah. I, I believe so....And if you be I don't know depressed and I don't know, then you don't have energy to fight. (A1, lines 989-693)

Optimism also helped the women adjust to each stage of illness. Many women talked about taking each stage step-by-step and feeling more hopeful with each new milestone. This positive attitude helped them deal with some of the difficult transitions and the uncertainty surrounding the ambiguity of a new modality of treatment. While there will always be good and bad days women talked about focusing on the positives. Another woman talked about feeling optimistic as soon as she heard the news from her surgeon that they removed all the cancer and the margins were clear. She remained positive throughout all her treatments and continued to remain hopeful for the future. A number of women talked about feeling hopeful and confident that everything was going to be fine and talked about having confidence in the medical system and advancement in breast cancer therapies.

Hope and optimism appeared to foster effective coping and became a significant factor in emotional and psychological well-being of the women. Quotes such as “look on the bright side”, “make the best of what you have”, “hope for the best”, “positive energy”, “maintain a positive attitude” or “everything will be okay” were descriptors in a number of the transcripts that illustrated how important this strategy became. However, the tumultuous journey of cancer continued to be marked with periods of emotional highs and lows. For seven women, fear of relapse continued to haunt them but hope and optimism was still described as a positive and effective way to help them face their fears.

6.4 Psychological Domain Summary

In summary, the psychological domain was illustrative of additional coping mechanisms the women utilized throughout their journey. Many unmet needs in many domains were highly complex and described in detail throughout the finding sections. The women also dealt with additional unmet needs related to loss of control over the illness experience, altered body image and decrease self-esteem. Therefore, finding strategies to help them cope with these complex needs was necessary for positive adaptation. Gaining personal control by changing their perspective of the illness or looking for positive opportunities as a result of the illness proved to be helpful. Additionally, utilizing distractions or taking a step-by-step approach to the illness also helped them feel less overwhelmed. Many women focused on their own wellness which also proved to be very important to help them feel more energized and in control of their personal situation. As the women proceeded through their journey, attributes such as resilience, self-reliance and optimism also fostered effective coping and promoted a positive self-esteem.

Spiritual Domain

The operational definition of this domain, defined by Fitch and colleagues, states that Spiritual Needs are based on “needs that are related to the meaning and purpose in life” (Fitch, 2009 pg. 19). The findings in this domain have been categorized according to four topic headings which include facing mortality, spiritual practices and beliefs, search for meaning and gaining new perspectives on life. The following table illustrates the heading summary in the spiritual domain.

Table 7: Spiritual Domain Summary

7.1 Facing Mortality
7.2 Spiritual Practices and Beliefs
7.3 Search for Meaning <ul style="list-style-type: none"> • 7.31 Seeking Understanding • 7.32 Meaning of Diagnosis
7.4 Gaining New Perspective <ul style="list-style-type: none"> • 7.41 Changing Attitude Towards Self and Others • 7.42 Giving Back to Others • 7.43 Re-evaluating Life • 7.44 New Beginnings
7.5 Domain Summary

7.1 Facing Mortality

Facing one’s own mortality was viewed from many different perspectives. Nine women expressed that they did not feel that the disease would end their lives. These women felt very confident with the advances in cancer therapies and had faith in the treatments they received and decision that they made. The women represented each of the age categories with the youngest being 34 years and oldest 84 years. The youngest woman who participated in the study talked about how her oncologist explained that the disease would eventually reoccur because of her age and nature of her illness but she still expressed optimism over advances in medicine. Two

women were highly spiritual and their faith in God gave them additional strength and peace with whatever the outcome would be. The oldest woman who participated in the study remained highly optimistic about advances in cancer therapies but felt comfortable with her own mortality.

Our times are in God's hands. I wasn't afraid... if I should die right away. I wasn't wanting to but I was ready if I needed to go... so that gave me peace. (D5, lines 586-588)

Additionally, a 50 year old woman talked about how her fear of mortality was an initial reaction to the diagnosis but she quickly dismissed the concern once she had time to absorb the news. She approached the diagnosis with a very positive optimistic attitude and was highly supported by family and friends. Conversely, the threat that breast cancer brings opened up many questions of mortality for the remainder of the women. Some women talked about how during the initial phases of illness concerns regarding their own mortality were very consuming. One woman described a very long wait to see a specialist and during that time was very overwhelmed with whether she was going to live or die.

Christmas was coming and I thought is this going to be it like you know am I going to be here for Christmas or is this my last one. (D2-2, lines 421-423)

Additionally, in a number of the interviews women talked about how their fear of mortality resurfaces with each new symptom, test results or visit with their oncologist. One woman who was approximately three years post completion of her therapy continued to worry on a daily basis that her cancer may come back and the potential exists that she could die from her illness. This ongoing fear of reoccurrence was described in a number of the remaining interviews. One woman talked about how she felt that the diagnosis will always present. She tries to overcome these fears but they still continue to haunt her. Other women talked about regrets in event that

they lose their life. It became evident in some of the interviews that regrets were mostly associated with what effect it will have on their family. Activities such not being able to watch their children or grandchildren grow up, missing important events or not being able to make an impact on someone's life were described.

If I would have ended up dying from this I wouldn't have seen the kids grow up, I wouldn't have seen my son get married, little things like that I wouldn't have... I wouldn't get to see my grandson's first girlfriends, things like that. (A4-2, lines 739-742)

Five women also talked about not feeling afraid to die. Death was referred to as being a natural part of aging, beyond ones control or in God's hands. However, the uncertainty surrounding potential mortality still remained. All of the women were asked if they would have treatment again in the event that the disease came back and only two women said they would decline therapy. The first 64 year old woman talked about how important quality of life was verses quantity of life and would spend her remaining time focusing on what is really important to her which was family. This woman talked about not feeling afraid to die and she described herself as a Christian and believed in heaven. The other 51 year old woman talked throughout her interviews how difficult it was to relocate and travel for treatment and stated she would not put herself through that again. All she wished for was to live long enough to see her dependent grandchildren become independent and prayed to God for that to happen. Additionally, the uncertainty surrounding if the second treatment would be successful was also part of her decision. As the women talked about issues related to their mortality, they also described many different ways of coping with their concerns. Some of the women worked through this process in internal personal ways whereas others utilized support from family, friends or outside

professional or peers. It also became apparent throughout the interviews that support from many different spiritual practices or beliefs were also highly valued.

7.2 Spiritual Practices and Beliefs

All of the women were asked to describe their sources of strength that guided them through their journey. Support from family and friends were the most common answers to this question however, spiritual practices or beliefs were also referred to. Seven women described engaging in spiritual practices such as attending church or prayer. Five of these women talked about their connection with a higher power, usually identified as God, and identified the importance of engaging in such a relationship. They talked about belief in God's presence and actively relied on God for support and guidance. Most of the women that talked about a connection with God described comfort in this relationship. One woman who continued to struggle emotionally throughout her illness described strength and comfort she received from God as her single most important source of strength. She also described a deep-rooted relationship with her pastor and his wife who were present during her early appointments when she felt the most vulnerable. When asked to describe her sources of strength, she responded accordingly.

God. He is, I can't I couldn't have done this without him, and prayer. And that's where I get all my strength from because but on my own I was weak and I had to really count on him especially going into the chemo. (B4, lines 173-180)

Another woman who was never married and lived alone most of her adult life struggled to make a decision regarding her surgical treatment options and felt it was a very personal decision between her and her "maker". In this situation, the woman was unable to attend her church based on her frail condition but utilized prayer and listened to spiritual tapes on a daily basis. Six

women attended church on a regular basis prior to their diagnosis and some of them talked about the close-knit church community in their rural setting as a source of support. However, four women found attending church to be too physically demanding or emotionally isolating and therefore did not engage in ceremony during their illness. Additionally, women talked about prayer as a source of strength to help them cope and used self-prayer at times of suffering, pain or plagued with other concerns. The remainder of the women did not speak of any specific spiritual practices or beliefs. However, one woman stated she did not believe in God but also felt that her illness was not caused because of her disbelief. Therefore, a variety of beliefs exist from those who were interviewed. Yet, based on the complexity of the diagnosis and individual coping mechanisms, finding meaning or gaining new perspective was also a way to find comfort in their illness.

7.3 Search for Meaning

Search for meaning was described by most of the women. Seeking understanding and meaning of the diagnosis were the discussions that evolved from the interviews and will be described further.

7.31 Seeking understanding. Women talked about cancer as an unexpected life event. Only four women attempted to attribute a cause to the illness. One woman talked about a significant family history of cancer in the family and always felt the possibility exist that she could develop cancer in her life time. Three women attributed their diagnosis to being plagued with stress in their lives. Others talked about feeling betrayed by their bodies and were left wondering if there was anything they did to cause the cancer. They reflected on their lifestyle choices or potential risk factors that may have attributed to the development of their illness. While struggling to reach an understanding the focus quickly changed.

*At first I thought why me but then I look at it different why not me?
And even the next person if they have Cancer. Why not them? It
just happens. Like it doesn't matter who you are right? (B1, lines
1389-1391)*

This alternative viewpoint became a common theme in a number of the interviews. At this point the majority of the women did not blame themselves for developing cancer. Quotes such as “not my fault”, “not to blame”, “targets good and bad people”, “drew the wrong straw”, “why not me”, “life is already written” or “it can happen to anyone” were revealed in many of the transcripts and finding a deeper meaning to the diagnosis was described.

7.32 Meaning of the diagnosis. Four women talked about how the diagnosis did not define who they were as a person and how they chose to overcome it became more of a focus. Two women described their journey as a unique and very personal experience and felt an overwhelming need for privacy because of this. In both situations the women were very selective about whom they would reach out to when in need of support or assistance. One woman lived alone her entire adult life and felt that asking for assistance when in need of privacy to be a very difficult aspect of her journey. Three women described cancer as a life-changing, never-ending event. A young mother with two small children talked about how her cancer will always have a presence in her life but refuses to let it become her focus. Another woman remained angry about the life-changing aspect of the illness and talked about wanting her life back to normal. Other women talked about how the cancer has changed their life forever. Six women minimized the diagnosis claiming that they have endured more stressful life events that were more difficult to deal with than their diagnosis and treatment. One woman talked about how she was a life survivor with multiple family and financial challenges and recently went through a difficult divorce. She talked about how her cancer was just another aspect of her life that she had to deal

with. Another woman cared for her ailing father for many years, whereas another lost her husband following a very difficult cancer journey. Both these women described these experiences as more challenging than their diagnosis. Other women talked about living with other chronic illnesses or other major life challenges as difficult aspects in their lives. One previously active woman loved rural life and outdoor hiking, found her chronic conditions affecting her mobility more debilitating than her cancer diagnosis.

*I think a lot of my other stuff sort of was bigger than cancer, I knew cancer was curable, you know I believe it is for me and if it comes back then it comes back, we'll deal with it at that time. But I found, I'm just finding loss of legs more devastating than, than my cancer.
(C3, lines 1326-1329)*

Ten women reflected on how the diagnosis and outcomes were beyond their control and therefore became attentive to things in their control or more important aspects of their lives. Four women focused on how others were worse off than they were which helped them gain new insight. Once the women were able to define what the diagnosis meant to them they then described a deeper meaning to the diagnosis by reflecting on the importance of life and gaining new perspectives.

6.34 Gaining New Perspectives on Life

For many of the women, their diagnosis had an impact on their lives which involved making active choices on what aspects of their life to focus on. Changing outlook towards self and others, giving back to others, re-evaluating life and new beginnings were discussed in many of the interviews.

7.41 Changing outlook towards self and others. All women were asked if they have changed as result of the experience. Four women expressed they have not changed in anyway

and would resume their lives as they did previously. All of these women were grateful that they were alive but felt the cancer was not a life-changing experience. Two of these women had other life stressors that became a focus for them. Another woman was still grieving the death of her husband and found that to be a bigger adjustment in her life. The final woman was happy with her life the way it was and remained very optimistic and supported throughout her illness. For the remainder of the women a more meaningful connection to self and others was evident. Two women talked about being more attentive and empathetic towards other people who may be walking down difficult paths. Another woman talked about being more realistic and strong and found a new appreciation of herself and her life. She talked about dropping a number of volunteer responsibilities and take time to enjoy life and family. Another woman felt an overwhelming sense of support and love from others during her illness found that she has changed her perspective on how she will approach life and express an appreciation of people as a result. The youngest woman who participated in the study talked about having a lot more self-respect and appreciation of her time. Another woman, who lived alone, was so ill during treatment and felt she could have died at many points in time. She is a very resilient woman and maintained her independence throughout her illness. Despite this she was so afraid during periods of her illness that now fearful events seem irrelevant in comparison.

There's less fear, I will tell you that, there's less fear, I know I've pushed the limits in some things because you think you've been so close, you know how far you can go. So there is less fear. You kind of get more bolder at things because really what have you got to lose, you know you've come so close so you're, you're pretty good, I don't know if I think I'm walking the line sometimes and I think I'll be okay and you just do it. (B2-2, lines 874-879)

This heightened sense of self-awareness remained evident in many of the interviews however awareness of others around them who were important also became apparent. At this point, family and friends became a focus of the discussions. Although, all the women appreciated the support they received during their illness, sixteen women emphasized the significance of family and friends and focusing on important relationships in their lives was their priority. The women talked about a heightened awareness of changes in social relationships, improved relationships with family members or new friendships that developed as a result of the experience. Cancer taught them new lessons in life and how they will approach relationships with others would also change. While a greater appreciation for self and others were heightened many other new lessons resulted from the experience. Women felt the need to express how thankful they were to have others who cared for them. Whereas others felt that need to give back to others in appreciation of the support they had received.

7.42 Giving back to others. Ten women talked about giving back to others as a result of their experience. One woman decided not to return to work and will volunteer at the child care center in her area. The oldest woman who participated in the study will continue to attend her support group and hopes to have an impact on others who will endure similar experiences. She also wants to volunteer at the senior's center in her area to spend time with those that may be lonely or need of company. Other women talked about developing deep bonds with others who shared similar cancer experiences and want to maintain these friendships into the future. Two women talked about wanting to volunteer as a cancer network resource liaison. While others described becoming mentors to other women with breast cancer and could see this in their future. These early reflections of interest were expressed by the women but not thoroughly explored in this study.

7.43 Re-evaluating life. All the women were asked to discuss their feelings surrounding cancer survivorship. Many quotes emerged from these discussions such as “grateful for life”, “blessed”, “a gift”, “feeling lucky”, “life can change in an instant”, “thankful for life”, “new beginnings”, “life is finite” or “second chances”. The women mostly just felt thankful to be alive and able to enjoy each new day. Not all the women felt that they were a changed person from the experience but the majority of the women stated that they had gained a new perspective which they found to be very impactful.

7.44 New beginnings. Cancer allowed the women to look at their lives and identify things that were meaningful to them. A number of women talked about how fragile life is or how life can change in a moment’s notice. Many women talked about the need to make the most in their lives and do things that are important to them as there are no guarantees in life. Many women adopted an attitude of “living for the moment”. During this re-evaluation process many described planning overdue vacations, working less or spending more time with family. Women talked about living life more fully, making every day count while enjoying an improved quality of life.

I think it makes me realize that you’ve got to live for now and like I don’t plan to do something two years from now, if I want to do something I want to do it now in case two years something happens and we can’t do something. I find that every day means more, just live each day and enjoy it. I find that I don’t look so far ahead anymore. (D2, lines 825-829)

A number of women talked about activities such as resetting priorities or not worrying about insignificant matters. Additionally, many women talked about the importance of family and relationships in their lives. A woman who was a primary caregiver for her grandchildren described this relationship as central to her activity. She wants to take the

time to make a difference in her grandchildren's lives which has now become one of her most important priorities. Relationships and family remained central to the discussion for the majority of the women. Opportunities to time to spend with family and friends and make more out of their lives were activities that they will engage in. Additionally, the majority of the women felt grateful to be alive and at peace with the decisions they made. Most women talked about feeling thankful and to take the time to enjoy life to the fullest.

Get to a good place in your life and be happy we're here. (B1, line 1396)

7.5 Spiritual Domain Summary

In summary, as difficult as the journey was for many of the women it was also marked with deep spiritual growth and discovery. For some of the women, facing their own mortality remained a very fearful process but many found ways to cope with ongoing uncertainty of the illness. Some women found solace and comfort in their spiritual practices yet were challenged to attend services because of other physical or social demands. Many of the women were unable to explain why the diagnosis happened to them and therefore moved through the process of finding a deeper meaning to the illness. Meaning and gaining new perspectives became a very personal journey for the women. Developing a new and deeper sense of who they were and what was important to them was an enriching process. This self-discovery helped the women reflect on how thankful they were for life and how new and existing connections they made with others would change them moving forward.

Chapter Summary

In conclusion, this chapter provided an interpretive description of the supportive care needs of the women who participated in this study. Each of the women talked about their journey

from initial presentation to the end of their treatment and the interpretation was summarized according to the categories in the supportive care framework. The women also provided thoughtful and insightful recommendation on how to improve services for people living with cancer from rural areas of the province which was highlighted throughout the finding section. Emphasis has been presented on additional challenges specific to living in the rural setting which will become the focused discussion in the following chapter. Chapter seven will present the discussion of the findings in the context of the current literature.

Chapter 7: Discussion of Findings

Chapter seven presents a discussion of the findings of the of the supportive care experiences of rural women living with breast cancer. This chapter will represent a discussion of the major findings in each of the domains in the supportive care framework, in relation to the current literature. The findings highlight specifics related to the rural experience as a focus of the discussion. The chapter concludes by highlighting the potential study limitations and strengths that warrant consideration.

Discussion of Supportive Care Domains

The primary purpose of this qualitative study was to arrive at an increased understanding of the supportive care experiences of adult women requiring treatment for IBC and who reside in rural Manitoba. The findings illuminate the lived experience of the women from each of the domains in the supportive care framework. The following will present a discussion of the major findings of this study featuring the rural experience.

Physical Domain

The physical domain was not without challenges in each phase of the treatment trajectory. The women described many physical symptoms that were commonly shared and many that were unique to their individual experience. Each modality of treatment had specific challenges from a physical perspective that are an anticipated aspect of cancer therapy. The literature abounds with research supporting that all women living with breast cancer will have unmet needs in the physical domain throughout the treatment phases of illness (Crane-Okada & Loney, 2007; McGarry et al., 2013; Schmid-Buchi et al., 2013; Wilkes et al., 1999). This study confirmed that complex physical symptoms are inevitable however living rurally creates additional challenges that complicate unmet needs in this domain.

First suspicion of illness is typically detected through screening mammography or palpable breast masses. Other advanced changes to the breast such as nipple inversions, dimpling, enlarged nodes in the axilla region or other skin or chest wall changes may also occur (Crane-Okada & Loney, 2007). In this study, four women entered the diagnostic stage of illness through screening mammography. Regular screening mammograms is an important secondary prevention strategy in cancer control and can lower death rates from breast cancer by up to 25 % in women 50 years of age and older (CCMB, 2014a). Additionally, breast screening rates remain consistent across regions of the province over the last 10 years with approximately 57-67% of women provincially involved in this program (CCMB, 2010, CCMB, 2014a). Many of the women were aware of the breast screening process but the majority of the women entered the system based on a palpable lumps, had advanced changes to the breast or some other benign physical symptom which pre-empted medical care.

Six women from three different regions of the province had a patient delay, time from symptom discovery to first medical appointment. Factors that affected these delays included age, winter travel, employment, fear of testing, aversion to medical treatment, and not having a family doctor in the rural setting to initiate testing. In a study by Stuver and colleagues (2011), the authors looked at factors related to the occurrence of delayed diagnosis in a retrospective study of 5,464 women with a new diagnosis of breast cancer. Younger age, minority race, decreased literacy, living alone and living outside a metropolitan setting were associated with higher risk of delayed breast cancer diagnosis. The authors also concluded the risk of delay in seeking treatment increased when multiple risk factors were present (Stuver et al., 2011). In an alternative review (Weber, Jiang, Gunfeld & Groom, 2017), the authors completed a scoping review of the literature and found other variables were also associated with delayed diagnoses in

breast cancer including non-lump symptoms, fear of disclosure and ethnicity. This study adds to a body of literature that support that delay in seeking medical care at first sign of physical illness is a complex process. Many factors need to be considered and increased awareness of these issues could help focus efforts to build programs to prevent delays of this nature and facilitate timely access to care. Additionally, travel challenges, access to rural service or family doctors in the community setting also proved to add additional challenges.

It is fortunate that the majority of the women, once they entered the health care system, received timely access to care within sixty days from diagnosis to time of treatment. This is keeping with the strategic direction of CCMB ‘In-Sixty day’ initiative which was launched in 2013 (CCMB, n.d. b). Unfortunately, two women did not have timely access to care and experienced significant medical delays, time from initial medical consultation to diagnosis or start of treatment. Both the women were from the SH region of the province and time of initial diagnostic mammogram to surgical intervention was 4 and 6 months in each individual case. An effort to ensure equitable and timely access to services, diagnostic testing and medical care in rural areas needs further consideration. Additionally, multiple factors need to be considered when patient or medical delays occur. This is a vitally important health topic bearing in mind the improved outcomes with diagnosis at the early stages of illness in this malignancy.

Travel was a major obstacle for the women in this study for a variety of reasons. From a physical perspective travel was associated with exacerbating already distressing treatment-related side-effects. Pain is commonly associated with breast cancer surgery. Acute pain occurs immediately following surgery and can be described as tenderness, shooting, pressure, or tightness and can last from 1-30 day post-surgery (Hovind, Bredal, & Dihle, 2013; Kulkarni et al., 2017; Vadivelu, Schreck, Lopez, Kodumudi & Narayan, 2008). Length of hospital stay

ranged from 1-4 days and painful travel post-surgery was described by many of the women. In a study by Vadivel and colleagues (2008) the authors found that the worst pain post-surgery for breast cancer is frequently reported at Day 2 assessment. Standard discharge dates post lumpectomy and mastectomy is within 24 hours post-surgery when the pain experience is heightened. Other factors associated with the post-surgical pain experience include emotional stability, feelings of anxiety and younger age (Kulkarni et al., 2017). Considering how vulnerable a woman is post-surgery by very nature of the experience combined with short hospital stays post-operative pain relief and time for discharge teaching about post-operative pain management is necessary to optimize pain control. Consideration should also be given to women from rural settings as travel will exacerbate the experience.

Many other symptoms would also be aggravated by travel. Fatigue is a distressing and common symptom experienced by the women. Fatigue was also associated with other factors such as decision to relocate for radiotherapy, driving safety, or increased travel fatigue. Other symptoms such as 'chemo fog' and radiation skin reactions would also pose challenges related to the travel experience. This study emphasizes that individuals who need to travel distances during the treatment phase of illness will experience exacerbations of treatment side-effects which is consistent with many other older studies reported in the literature (Fitch, et al., 2003; Hegney, et al., 2005; Martin-McDonald, et al., 2003; Payne, Jarrett & Jeffs, 2000). Living with treatment-related side-effects is a difficult and enduring process. Whether travel occurred on a daily basis or as required, it imposed a burden on the individuals by aggravating a variety of symptoms. Given the inevitability of travel for the rural population, it is important for HCP to be aware of the potential travel-related symptoms that can arise and to facilitate improved symptom management or help the patients plan for additional symptoms they may expect.

Another finding in the physical domain was lack of access to experience HCP or emergency services to help the women manage complex oncology-related physical problems or emergencies. Transitioning through the physical demands of illness and unique treatment-related challenges are inevitable. It is frequently noted in the literature that managing complex physical cancer-related demands are accelerated for our rural population based on access to experienced medical and nursing support in rural areas (Girgis et al., 2000; McGrath, 2001; Wilkes et al., 2000). Oncologic emergencies occur frequently in the cancer population and can be life-threatening requiring immediate access to emergency services (Myers, 2007). The emergencies that were present in this study were hematologic or infectious in nature. However, other emergencies in this population can occur such as metabolic, cardiopulmonary or infusional-related emergencies that could prompt urgent medical intervention (Crane-Okada & Loney, 2007; Myers, 2007). Ongoing challenges exist in rural health care which were highlighted in a report mandated by the Government of Manitoba in 2017 with the aim to reframe health care services in our province (Peachey, Tait, Adams & Croson, 2017). The report featured emerging challenges that define rural health such as high level of on-call responsibilities for HCP, long distances to secondary and tertiary referral centers, lack of specialized services, insufficient numbers of general practitioners, absence of diagnostic equipment, limited ambulance service and sparsely populated catchment areas which are unique to the rural experience. Other factors that need consideration include the culture of rural practice and professional isolation and support (Peachey et al., 2017). Managing complex physical symptoms or dealing with life-threatening disease or treatment-related emergencies is a reality of people living with cancer. Efforts to ensure rural people living in our province with cancer have access to emergency and experienced HCP in rural settings to manage these unique challenges is imperative.

Health care professionals working in rural setting often are faced with much greater role diffusion than providers in urban or specialized settings. Nurses will often be expected to perform diverse tasks and are often described a practicing generalist (Long & Weinert, 1989, 1999, 2010). Rural nurses often work in isolated settings are cut off from the professional mainstream or find themselves in situation where there is no collegial support to assist them in complex practice roles (Long & Weinert, 1989, 1999, 2010). A Cancer Help Line which is triaged by experienced oncology nurses assists patients and rural practitioners to manage challenging oncology-related problems and emergencies. This new and under-utilized service should become part of the discussion (CCMB n.d. a; Barb Hues, Nurse Educator, CCMB personal communication, November 30, 2017). This also has important implications for nursing education at an undergraduate level and the need for continuing education opportunities for nurses practicing in rural settings.

The significant role of the rural CCP and rural home care services requires emphasis. The HCP in these settings were instrumental in the overall patient journey and provided the support the women required to manage their complex physical needs. Recommendations have been brought forward to the Government of Manitoba to upgrade home care services at a provincial level. Training for home care aides to match acuity and to ensure equitable access to home care services in all regions of the province were important features in this report (Peachey et al., 2017). Considering 40 % of our oncology population lives in rural or remote areas of the province, pragmatic recommendations such as this bode well for people living in our province with cancer. The role of the CCP will be discussed under the other domain discussions.

Informational Domain

All patients with cancer will require individualized information when they enter the cancer system based on the needs of the person and complexity of the experience (Fitch, 2009; Mills & Sullivan, 1999). Additionally, information-giving is influenced by multiple factors. No definitive method of providing information will suit all needs of individuals (Bastable et al. 2011; Mills & Sullivan, 1999). The women in the study had a variety of learning needs and utilized many modes of learning to interpret the complex information that was presented. Additionally, their informational needs were heightened early on in the diagnosis when emotions were escalated and travel demands were significant. Moreover, some women appreciated more information whereas other felt it was overwhelming and difficult to process. These findings are consistent with the literature featuring complex informational needs of breast cancer patients and principles of teaching and learning in complex health care settings (Au et al., 2012; Bastable et al., 2011; Fiszer, et al., 2013; Franklin et al., 2009). These findings are also supported by other studies that emphasize that priority “need to know” information and priority instruction is a vital component of patient education when faced with a cancer diagnosis (Au et al., 2012; Luker et al., 1995; Mercuri & Kallady, 2005; Wilkes et al, 2000). It is important for all HCP to be aware that teaching and learning in complex health care situations require tailored instruction specific to needs and learning styles of the individuals. These strategies should be considered for all persons living with cancer however living in rural areas poses other unique obstacles which will be featured in the following sections.

Health care providers including rural family doctors, oncology specialists, in-patient hospital staff, nursing staff, nurse navigators and interdisciplinary professionals were the key informants the women used to gain the information they required. This is consistent with the

literature whereas HCP are the primary means of obtaining information and other modes of learning such as family members, the internet, written materials, friends, co-workers, support groups, scientific research reports or foundations become secondary (Bastable et al., 2011; Walsh, et al., 2010). As the women transitioned through the journey, different providers were important and many of these relationships were highly valued however challenges did exist based on limited access to specialists and experienced multidisciplinary teams in rural hospital or primary care settings. The findings in this study are consistent with a body of literature that features multiple challenges in rural settings related to access to information and professional support to inform decisions (Duggleby, et al., 2010; Gray, et al., 2004; McGrath, 2001; Wilkes, et al., 2000; Wilkes, et al., 2006). Rural people are often faced with these challenges therefore, it is important to consider 'place' as an analytical tool to assess geographic issues that are central to rural health care. From a physical construct distance and location are two major barriers which lead to inequities in service provision for people living in rural areas (Castleden, Crooks, Schuurman & Hanlon, 2010; Giesbrecht, et al., 2016). Physical distance between services and users of service, winter travel, travel distance, geographic barriers and access to services in rural settings are barriers for cancer patients in rural communities. It is imperative to have qualified HCP and other resources available to meet ongoing informational needs. The CCP and navigation programs have addressed some of these unmet needs however further consideration to 'place' as a tool to enhance service and programs and generate discussion of these real practice issues should be explored.

The study findings also provide insight into the importance of informational delivery strategies and good communication with HCP. All HCP will provide informational support at points in time in the treatment journey but continuity of care can be further fragmented

considering the barriers that face our rural population. Continuity of care can be described as coherent and connected care that takes patients' unique needs into consideration from a relational, informational and management perspective (Easley, et al., 2016). Good communication, patient and family-centered care, positive relationships with HCP, clearly defined health care roles and team functioning are essential components to ensure continuity and collaborative practice delivery models are achieved (Canadian Interprofessional Health Collaborative [CIHC], 2010; Easley, et al., 2016). Delivery of complex cancer services to rural individuals requires a collective, coordinative and collaborative approach to service delivery that requires further attention considering the complex informational needs that comes with living with the illness.

The family doctors and oncology nurses in the rural CCP became the primary means of informational support during the chemotherapy phase of the journey. Nurses can play an integral role in case management and providing information services to people living in rural areas which well documented in the literature (McConigley, et al., 2011; Wilkes, et al., 2000; Wilkes, et al., 2006). Furthermore, nurses who work in cancer settings in rural areas have the additional expertise to provide coordination of cancer services and have expertise in cancer-related problems and emergencies to further assist in the complex care (Wilkes, et al., 2000; Wilkes, et al., 2006). Nurse navigators were also an important service expressed by the women who accessed this service until such time as the women utilized the CCP nurses for support. However, the CCP nurses are mostly situated to provide support and information during the chemotherapy phase of illness. Disease site nurse navigators are positioned to provide patient and family-centered services, patient education and advocacy, serve as liaison between physician and treatment staff, facilitate the web of diagnostics and provide overall case management through

each of the phases of the cancer journey (Farber, Deschamps & Cameron, 2002). Nurse navigators in both the rural sites and at WCCH were under-utilized in this study. Programs such as CCP and navigation improve access to service, provide nursing expertise and promote continuity of care and additional support for cancer patients.

Another finding in the study was the under-use and limited access of interdisciplinary care in rural settings. Women talked about potential benefits that could be achieved from the care of physiotherapists, pharmacists, dieticians, social workers or counsellors throughout their descriptions. Collaborative care is when several HCP work together in partnership with patients and families to provide high quality care and is linked to better health outcomes, reduction in hospital stays or patient complications, decreased clinical errors and enhanced patient satisfaction. Additionally, it maximizes HCP skills and expertise and helps teams deliver more efficient and cost-effective health services (WRHA, n.d. c). An initiative that has been recommended to the government of Manitoba includes expansion of MyHealth Teams (MyHT) in rural and remote areas of the province (Peachey et al., 2017). This primary care service delivery model includes integration and collaboration of a roster of providers, including physicians, nurses, nurse practitioners, psychologist, dietician, physiotherapists, occupational therapists, advanced paramedics and pharmacists through electronic means or maintaining regular rotations through remote or rural communities (Peachey, et al., 2017). All these initiative are important to improve continuity of care and facilitate a collaborative partnership between HCP and the patient and family (CHIC, 2010; Easley, et al., 2016). Considering complex informational needs of women living with breast cancer and how cancer information is directly linked to the HCP services, coordination and collaborative is imperative. As a woman transitions

from primary care through diagnosis, treatment and back to a primary care setting coordination and smooth transition of services is of the essence.

Social Domain

Social relationships serve as an important function in people's everyday lives. Positive supportive networks play a role in improving health outcomes, physical wellbeing, foster coping and adjustment to the cancer experience (Callahan & Morrissey, 1993; Fitch, 2009; Usta, 2012; Yoo et. al., 2010). Support can be measured in many ways and received from many different avenues which include family, friends, peers, community, religious affiliations, health care professionals or self-help groups (Pender et al., 2011). As the women talked about their experience it became apparent that the primary sources of social support was from immediate family members including their spouse, children, adult children, siblings and parents. The definition of family was different for each participant and level of support from the family members also varied. The role of family was very important to assist the women to meet their needs in many of the domains in the framework. However, the women experienced challenges within their intimate family circle related to changes in roles, telling family, dealing with family members' responses to the illness, decision-making, worrying about children or spouse, increased dependence, and changes in lifestyle or family dynamics. These are common challenges that all people living with cancer commonly face and need to work through in each phase of the journey (Fitch, et al., 2009; Langhorne, et al., 2007). The women distinctively worked through their individual obstacles and were able to positively reflect on the critical impact that their family had on their overall journey. The role of the family caregiver and impact of the diagnosis on the spouse was not thoroughly described in this study. Family care-giving is a multifaceted role and additional demands will be imposed by the very nature of the rural

experience and additional challenges it creates. Opportunities exist to develop research initiatives around the concept of family care-giving from the rural perspective.

Extensions of support were also described by some of the women from friends, neighbours, peers, co-workers, congregations or the wider community. The literature abounds with research illustrating characteristics of rural community living. Rural life is often associated with close social connections, kinship and community adhesion (Castleden, et al., 2010; Duggleby, et al., 2010; Gray, et al., 2004; Pesut, Robinson, Bottorff, Fyles, & Broughton, 2010; Rogers-Clark, et al, 2002). In a study by Pesut and colleagues (2009) the authors found that the importance of rural lifestyles and extensions of support was instrumental in the overall well-being of the rural individuals living with advanced malignancies. Friends would provide assistance in many IADL. Community-based organizations could assist with travel and expenses or community fundraisers were held to offset the costs of illness (Pesut, et al, 2010). Similar findings were noted in this study and the women that leaned on extended support networks and positively described the impact it had on their overall. The role of social support is widely documented in the health literature and linked to improved health outcomes and psychological adjustment to an illness experience (Callaghan & Morrissey, 1992; Lugton, 1996; Reblin & Uchino, 2008; Usta, 2012; Yoo, et al., 2010). The strong sense of belonging and connectivity that exists in rural areas is an important social capital tool in health care settings. Social capital in this setting is defined as a “link between an individual and his or her immediate social environment; it includes concepts such as social networks, mutual trust, civic participation, community engagement, and other institutional relations that can affect the health of the individuals” (DesMeules, et. al., 2012, p. 41). The authors also postulate that the possibility exists that rural community characteristics have a direct relationship on wellbeing and self-

perceived health of individual living with illness (DesMeules, et al., 2012). Additionally, considering 'place' from a social construct should also be considered by the very nature of the social environment in a rural setting. Opportunities exist to 'make a place' for socially-directed support and service opportunities in rural settings (Castleden, et al., 2010; Giesbrecht, et al., 2016).

In this study, the social environment of living in a rural area also posed specific obstacles. A number of women felt their diagnosis was a very private and personal experience and found living in a rural area invaded their privacy based on a lack of anonymity and close-ties in the community. Many communication challenges exist such as disclosure of the diagnosis for fear the word would travel quickly, receiving opposing views or inappropriate comments from others, feelings of embarrassment over the diagnosis or not wanting to discuss private issues. Other social challenges included changes in long-standing relationships, knowing your caregivers or other cancer patients receiving treatment in the local CCP. These findings are also supported in the rural literature proposing that living in close-knit communities can lead to further isolation and lack of privacy when faced with a cancer diagnosis (Gray, et al., 2004; Long & Weiner, 1989, 1999, 2010; Rogers-Clark, et al., 2002). As a result, isolation did become a problem for many of the women who participated in the study.

Social isolation is an important concept in chronic illness (Biordi, 2006). Social isolation is also noted in other rural study findings in the scholarly literature (Hegney, et al., 2004; Gray, et al., 2004; McGrath, 2001; Rogers-Clark, et al., 2002) Many of these described challenges would result in the women isolating themselves from social situations such as avoid shopping, taking walks, attending church or avoiding discussions or other situation when they would be around people. Some women felt very uncomfortable in the rural CCP based on the

close quarters and lack of privacy in the setting. Alternatively, women also talked about others withdrawing from them because of their discomfort with the diagnosis. Social isolation can occur at a personal, family, organization or community level however families are likely to remain in the social network which can lead to other challenges such as caregiver strain (Biordi, 2006). Social isolation can have both positive and negative outcomes which should be considered by HCP.

Social isolation is not always viewed as negative experience in the face of chronic illness and can be used a defense mechanism to avoid situations of increased stress and promote personal renewal. The isolated will often use a supportive networks system to enhance mental health, maintain support or alleviate stress (Carpenito-Moyet, 2004; Biordi, 2006). However, prolonged isolation can impact healthy relationships, impair roles, affect mental and physical health and lead to denial, depression or loneliness (Carpenito-Moyet, 2004; Biordi, 2006). Nurses working in rural areas need to be aware of the impact that social isolation could have on a person living cancer and the added dimension that living rural can bring into the equation. Isolation can occur at the social level but can also result from physical challenges such as neutropenia or hair loss. Additionally, isolation could also result from limited access to professional expertise or relocation from family and friends while receiving medical care in an urban setting. Consequently, the scope of social isolation is an important finding in this study and requires tailored intervention and astute assessment from HCP.

Practical Domain

Practical needs encompass a broad range of activities that are required to meet the daily needs of individuals (Fitch, 2009). This study highlights that there are many practical challenges that are endured when faced with an illness such as breast cancer. Dealing with treatment-related

toxicity will unavoidably affect all patients with cancer undergoing complex treatment plans or multiple modality therapies (Crane-Okada & Loney, 2007; Langhorne et al., 2007). Therefore, managing ADL and IADL can pose specific challenges and inevitably additional support may be required (Miller, 2012). Functional status can be broadly defined as the capacity for a person to function in areas such a physical health, self-maintenance, daily roles or other social or intellectual activities of daily life (Mitchell, 2007). When a person's functional status declines from chronic illness such as cancer it can markedly affect their quality of life and adjustment to the illness experience (Armstrong, 2003; Mitchell, 2007). Additionally, multiple factors related to physiologic status, situational demands, performance and duration and intensity of symptoms can also lead to further functional decline (Lenz, Pugh & Milligan, 1995). Chronic illnesses, complex care-giver roles, employment, living alone or limited support also create additional practical challenges for some of the women which affected their ability to meet some of their basic needs. Therefore, it is important for HCP to evaluate symptom distress, functional status and other contributing factors in their assessment of person's living with cancer.

Many functional assessment tools are readily available as a guide (Mitchell, 2007). Currently at CCMB a 'Compass Tool' which is a comprehensive problem and symptom screening tool to evaluate a person's degree of symptoms, functional status and how it affects their daily life from an emotional, social and practical perspective is currently being utilized (Barb Hues, Nurse Educator, CCMB, personal communication, June 29, 2017). Since it is unavoidable that people living with cancer will experience some degree of symptom distress and functional decline based on the very nature of the toxic treatments, individualized assessment will be required. The study findings suggest that supportive networks played an important role in assisting the women to meet their basic needs. However, many other practical challenges also

occurred directly related to the rural experience that also needs to be factored in when considering how a person is managing with the illness experience or how it affects their functional capacity.

The demands and challenges associated with travel was an important finding in this study. The women from all regions reported many trips to an urban setting. The study findings suggests that the long travel days and frequent commutes to the city for care adds an additional dimension of stress and burden on people living in rural settings which has been noted in the literature (Davis, Girgis, Williams & Beeney, 1998; Gray et al., 2003; Fitch et al., 2003; Hegney et al., 2004; Martin-McDonald et al., 2003; McGrath, 2001). In this study practical decisions were made around the demands of travel such as decision to relocate for radiation, maintaining employment or caring for home or pets. Other stressors included concern for finances, travel safety, poor road conditions or discomfort driving in an unfamiliar city. Challenges for the northern women were based on air travel, long bus rides, NPTP or unable to have an escort accompany them to appointments. This study confirms that significant obstacles are imposed on rural people required to commute for medical care and can have a significant impact on their experience. Two studies noted in the review of the literature sought to understand if treatment decisions would be based on the burden of travel. In both of these studies travel burden and distance were significant barriers and treatment decision may be made based on geography rather than the best interest of patient and therefore the burden of travel may carry serious implications (Celaya et al., 2006; Punglia et al., 2006). Fortunately, this did not occur with the women participating in this study. However, it is important to be cognizant of the potential barriers that are posed by travel from a physical, social and practical perspective. Few studies of this nature have been conducted in the Canadian cancer population and would provide insight into

additional challenges that rural Canadians may face such as poor driving conditions, long winters and long distances to treatment centers. If the potential exists that people opt out of treatment based on travel burden it becomes a vital health care concern.

Relocation was another finding that requires discussion. Housing and accommodation are basic practical needs, so when affordable, comfortable and supportive housing for rural cancer patients was available, the experience was highly valued. These services also have the option for extension of support by the very nature of who uses the service. Developing bonds with other people relocated for medical care can help offset the loneliness of lengthy relocation away from family and friends. This is consistent with other studies and is reported with high degrees of satisfaction (Fitch et al, 2003; Hegney et al., 2005; Martin-McDonald et al, 2003; Payne et al., 2001; Pesut et al, 2010; Wilkes et al., 2006). Women also used other housing options to meet their needs such as lodges, hotels and staying with friends or family. However, the financial implications that are associated with relocation became an important finding that requires consideration. In this study all the women, with the exception of one Indigenous woman, had to pay out-of-pocket for the cost of relocation. Currently in Manitoba, First Nations and Inuit Health Branch (FNIHB) covers medical travel, accommodation and meals for all First Nation people who live on reserve (Government of MB, 2016). Off-reserve First Nations people will utilize other means to have their housing costs covered such as Employment Insurance Assistance (EIA) or KTC medical services which was the case for the women who participated in this study. These programs provide housing in places such as boarding homes, hotels and in some situations will utilize supportive services or lodges.

The nature of the accommodation also requires discussion. When comparing relocation experiences amongst the women two very negative experiences became apparent and require

further illustration. The first woman had her housing arranged by KTC, in a hotel, without a medical escort, leading to loneliness and feelings of isolation. The second woman could not afford any of the housing options and relocated with a distant friend in a sub-standard housing situation. Both of these women lived too far to commute for radiation. These examples illustrate some of the challenges that rural people living with cancer may face related to relocation and the accommodation may not always be optimal. When the option exists many people may choose to commute based on barriers such as cost or limited housing options but the burden of travel will then be escalated. Conversely, if relocation is required the out-of-pocket costs associated with relocation will escalate and other challenges such as sub-optimal conditions, missing home, isolation from family and friends or unable to maintain employment will also pose challenges. These study findings are consistent with other scholarly works reported in the literature (Fitch et al., 2003; Lilliehorn & Salander, 2016; Martin-McDonald et al., 2003; McGrath, 1999; McGrath, 2001). Relocation or decisions to commute for treatment are highly variable and depends on many factors such as financial resources, available social support, distance to the commuting center and physical inability to travel. These are realities that our rural cancer population will inevitably face. There are no easy solutions for this problem however promoting social organizations that address the need for supportive and affordable housing for our rural population is essential. It is also important to consider other factors related to relocation such as isolation from family, financial implications or challenges leaving the family home. Therefore, exploring potential resources available for patients and families to assist with this complex issue should be at the forefront of attention for HCP and social advocacy groups.

The financial implication of living in a rural area when faced with a cancer diagnosis is another important finding in this study. Out-of-pocket costs endured by the women were

significant and comparable across regions of the province. Many studies exist in the scholarly literature featuring both direct and indirect out-of-pocket costs that are incurred as a result of a cancer diagnosis (Gray et al, 2003; Longo & Bereza, 2011; Longo, Deber, Fitch, Williams & D'Souza, 2007; Mathews, West, & Bulher, 2009; Nip, Powell, Chabner & Moy, 2015; Wagner & Lacey, 2003). Furthermore, literature also exist that feature the potential for individuals to alter care decisions based on the financial impact imposed on them (Burman & Weinert, 1997; Mathews, et al., 2009; Nipp et al., 2015; Wagner & Lacey, 2003). In 2010 CCS, MB Division in partnership with Canadian Cancer Action Network, joined forces to explore the 'Financial hardship of cancer in Canada: A call for action' through a detailed literature review in combination with qualitative interviews with front line care providers, cancer survivors and family members (CCS, 2013b). The authors of this document described the financial hardship as two-fold including dramatic decline in income and rising out-of-pocket expenses which affect all Canadians living with cancer. However, the cost of medical travel including fuel, vehicle costs, accommodation, a companion, taxi rides, child care and parking are additional costs which disproportionately affect people living in rural communities (CCS, 2013b). Additionally, people in rural areas are more frequently older, retired, self-employed, have decreased income and occupation skill level or work part-time (Alasia, 2005; Curto & Rothwell, 2002; Long & Weinert, 2010; DesMeules et al., 2012; Plessis, 2004; Singh, 2002). The findings in this study support the vast literature which highlights the economic disparities for rural people living with a cancer diagnosis exist. This is a long-standing problem that has a potential for serious implications such as altering care decision or deferring certain therapies that are not accessible and should be a focus of attention for researchers and policy makers.

The financial burden of illness has been highlighted in the report by Peachey and colleagues (2017), which has addressed some of the rural health service challenges including the significant costs of medical travel as a major barrier to providing and accessing health care services. The report highlights some key initiatives to address some of the rural challenges such as equitable distribution of funding for medical travel, increasing the use of telehealth services and expanding interdisciplinary teams in rural primary health care. However, other initiatives such as re-designation of rural hospitals, changing the model of service delivery in rural emergency rooms and centralization of speciality services (Peachey et al., 2017) will continue to challenge rural people living with cancer and ultimately add to the economic burden related to travel and relocation. A collective effort with other community and social organization will inevitably be required to address this complex, social issue. Advocacy groups such as health, labor, anti-poverty, Indigenous or professional organizations, service clubs, charitable organizations and foundations are well positioned to assist. Increasing awareness at this level would be warranted (CCS, 2013b). A coordinated approach to addressing this important health care topic is required.

Emotional Domain

It became clear in this study that the emotional journey of cancer is a very unique and individual experience and the degree of emotions also varied. Many unmet needs and additional challenges featured in the prior discussions based on the rural experience ultimately impacted the women adding to the emotional burden and stress that they felt from the diagnosis. In addition, complex emotions were described by the women directly related to the cancer experience including shock and disbelief, denial, guilt, uncertainty, feeling anxious, anger and fear. Additionally, how the women dealt with their complex emotions also proved to be variable. According to Fitch (2009) emotional distress is a natural and anticipated response to an illness

such as cancer and will be experienced by all cancer patients. Even those who have adequate resources and coping skills will experience emotional upheaval during their illness. Escalated emotional distress if left untreated can ultimately compromise adherence to treatment, increase utilization of additional health services, and elevate costs for care (Fitch, 2009). In this study, most of the women were able to adjust to the emotional resulting from their experience but not without challenges. However, two emotions require further discussion including fear and anger.

Fear was one of the most commonly described emotions amongst the women, although not all the women were afraid. Many had faith in the medical system and treatments that they were receiving. Others voiced fears related to the urgency to have cancer removed, mortality, leaving family behind, reoccurrence, cancer spreading, treatment not working, medical check-ups, procedures or treatment toxicity which challenging for them to deal with. This study validates what was noted in the literature review with fear as a commonly reported outcome of a cancer diagnosis including fear of physical outcomes, treatment and toxicity, changes in quality of life, and reoccurrence (Ellegaard et al., 2017; McGinty et al., 2016; Thewes et al., 2016). Fear can also be compounded when faced with a diagnosis when living in a rural setting. Fear of financial concerns, separations from family or friends or poor quality of care can be mounting concerns (Burman & Weinert, 1997). According to Shell (2007) an initial diagnosis of cancer can be one of the most emotionally difficult times in the cancer journey. Fear can become crippling and is often rooted in uncertainty. During this stage of the illness other feelings such a shock, denial or anger can also arise resulting in emotional distress that is difficult to overcome. During this initial period it is often difficult to comprehend any information that is being relayed by the HCP because of complex web of emotions (Shell, 2007). Other studies reveal that fear can

also be linked to uncertainty and having up-to-date, relevant and understandable information is essential to help alleviate this sense of uncertainty (Ellegaard et al., 2017; Shaha, et al., 2008).

It was noted in this study that during the initial diagnostic stage of illness, fears were heightened for many of the women and retention of information was very difficult. Invariable, this can impact all persons living with cancer from both urban and rural settings, however, escalated for rural people based on geographic location and isolation from services. Several clinical implications can be considered which have already been discussed however it emphasizes the need for increased resources and smoother transition from primary care to cancer care facilitated by interdisciplinary MyHT and navigation support. These HCP would be well positioned to provide the additional support and information the women need during this vulnerable stage. Uniting Primary Care and Oncology (UPCON) is another initiative that is worth discussion (CCMB n.d. c). The program was established in 2004 and links primary HCP to oncology expertise at CCMB. Currently there are 50 primary health care clinics, 24 clinics situated in rural sites across the province. Health care providers working in primary care have access to newsletters, oncology training, professional development opportunities, electronic access to patient records and a cancer helpline. It provides opportunity for better coordination of care between providers and helps facilitate smoother transition between services (CCMB, n.d. c). Health care providers in primary care setting are often the first point of entry of a cancer diagnosis when fears are escalated. It is unclear if the women had family doctors who were linked to this program however many of the women suggested better communication between rural and urban HCP was required. Therefore, enhancing UPCON services and resources in rural areas to stream-line a smoother transition to cancer care would be useful. Additionally, nurses need to be aware that this is a very difficult time especially for people travelling from rural

settings and cognizant of the need for extra time and attention that may be required to address these very real fears.

Anger was another emotion that requires discussion. Only one woman expressed anger towards her illness which later turned to anger towards the health care system. In this situation, providing and caring for her grand-children were her most important priorities and therefore travel and relocation were the biggest challenges she faced throughout her journey. This example illustrates how impairment of roles as a result of a cancer experience can have a direct impact on emotional wellbeing (Larsen, Lewis, & Lubkin, 2006). It also emphasizes that isolation from family, disruptions in family life, changes in living arrangements, organizing child care and worries about finances or employment are real problems that impact rural cancer patients needing to travel to urban centers (Duggleby et al., 2010; Fitch et al. 2003; Gray et al., 2004; Hegney et al., 2005; Martin-McDonald et al., 2003). In this situation, she became powerless to the health care system which is another important concept related to chronic illness (Onega, 2006). Health care systems are designed to assist individuals and families but obstacles such as access to services or lack of resources can ultimately lead to feelings of powerlessness (Onega, 2006).

Other women also voiced feelings of anger towards the health care system based on the treatment they received both in urban and rural settings. Many examples are provided in the presentation of the findings where women felt disrespected from HCP or they lacked compassion, inattentive or inexperienced HCP, decreased quality of care, long wait times, cancelled appointments after lengthy travel and medical errors were illustrations of additional challenges. These examples again emphasize how powerless a person is to the health care system and quality of care can have a direct impact on emotional wellbeing. Considering the complex

emotions that occur when faced with an illness such as cancer and compounded by the rural experience it is imperative that we find ways to stream-line services and provide additional supportive services to assist people living with cancer who live in rural areas.

Many other complex emotions were expressed by the women and they utilized multiple strategies to help release their emotions. Venting, crying, spending time alone or with family, engaging in other activities such as yoga, listening to music, art therapy, meditation, reading, gardening and journaling all proved to be useful strategies. Additionally, family, community, professional and peer support were instrumental in helping the women through the many difficult emotions that they endured. Many studies in the literature reveal that women with breast cancer will use a variety of techniques to meet their emotional needs but social support is often the most impactful (Koopman et al, 2001; Lugton, 1996; Yoo et al., 2010) The positive role of social support has been discussed under the social domain discussion and it was evident the impact that family and community had in the overall wellness of the women. Therefore, the focus of the following discussion will be on the role of peer support and nurses in the rural CCP.

Peer support can be defined as “a supportive relationship between two people that have a lived experience in common” (Mental Health Commission of Canada [MHCC], 2014, para. 1). Peer support provides emotional and social support while considering wellness of the whole person. It emphasizes health and recovery rather than illness and disability. Peer support can range from both informal supports to more structured supportive service in formal settings (MHCC, 2014). Self-efficacy is a concept which was initially published by Albert Bandura in the 1970’s (Bandura, 1977, 1982, 1989) and defined as “a person’s belief about their capabilities to exercise control over their own level of functioning and over events that affect their lives” (Bandura, 1989, pp. 118). Two antecedents associated with this concept include vicarious

experience and verbal persuasion. Vicarious experience is achieved by social modeling. Witnessing people in a similar circumstances withstand a sustained effort, raises the observers belief in their own capabilities to master a similar task. Verbal persuasion by means of positive reinforcement will mobilize individuals to feel more capable (Bandura, 1977, 1982, 1989). Research suggests that high levels of self-efficacy can significantly influence health behaviors and promote emotional adjustment to the cancer experience (Lev & Owen, 2000; Merluzzi, & Martinez-Sanchez, 1997; Newman, 2006; Palesh et. al, 2006). Peer support and support groups evolved from the concept of self-efficacy by using vicarious experience and verbal persuasion strategies in health care settings (Bastable et. al., 2011; Lev & Owen, 2000; Palesh et al, 2006). In this study the women utilized many informal peer supports throughout their journey. They described entering into supportive relationships with friends, family or other community members with cancer or having supportive conversations with other cancer patients in the CCP, relocation facility or through the volunteer driver programs. Only three women utilized formal peer support through an on-line chat, support group in a rural community and the peer support program through WCCH. In most of the descriptions peer supports proved to be very impactful.

Many formal peer and support programs exist in Manitoba and can be found on the CCMB website. Support groups specifically for women with breast cancer are mostly facilitated in Winnipeg however intermittently they are offered in a variety of rural sites across Manitoba (CCMB, 2017). Considering the impact of peer support on a person's emotional adjustment to the illness experience and the under-utilization and limited availability of formal peer supportive initiations in rural setting, attention is required. Opportunities exist to enhance current peer supportive services that are already available or design alternative methods of delivery for people who live in rural settings. It is imperative to consider emotional self-efficacy as a concept to help

women cope with the illness experience or other stressful events that impact them and ensure additional services to person's living in rural or remote areas are available.

It was also clearly evident throughout the interviews that the nurses in the rural CCP were a significant source of emotional support for the women. The women described personal and intimate care and developed deep connections with these providers. Many of the women described feeling so well cared for during the chemotherapy phase of illness that the care and support was sorely missed once their treatment was completed. The nature of the interpersonal relationship between nurses practicing in rural settings and their patients is often very different than nurses working in urban settings (MacKinnon, 2014; Scharff, 2010). There is frequently an interpersonal closeness and dynamic that is unique to the rural setting and rural nurses' job satisfaction and dedication to their work is intertwined with their contentment with living in a particular rural community. Nurses in any setting are likely to develop close relationship with their patients, however rural nurses are in a unique situation where they are personally acquainted to those around them increasing the depth of the encounter and has been described in the literature as "relationship work" (MacKinnon, 2014, pp. 323; Scharff, 2010). Additionally, rural nurses are often positioned to mobilize community strengths by knowing the people in their community which can become central to rural nursing work (MacKinnon, 2014). In the dissemination of the study findings it is important to highlight current services that are positively viewed and the work that the nurses are doing in the rural CCP is certainly one of the highlighted and positive services that was captured in this study. However, challenges also remain related to as physical constraints in the rural CCP including lack of privacy to have intimate conversations with patients. Therefore, the site of care considering the social place of cancer service should become part of the discussion (Giesbrecht et al., 2016). Further ethnographic research based on

the social and cultural aspect of care in rural CCP settings would be potential grounding for future research. Additionally, the challenges associative with rural nursing were beyond the scope of this study.

Family's emotional response to illness was briefly described in the study findings. A diagnosis of cancer will enviably affect the entire family. In this study, there were many illustrations where family members were not coping well with the diagnosis of their family member which added an additional dimension of stress and worry for the women. These challenges were mostly based on different views surrounding treatment decisions. In many of these situations the family members were unable to attend the meeting with the specialists when treatment decisions were discussed. Families will experience many of the same emotions and inherent stress that the person with cancer will face (Shell, 2007). It is important for nurses to guide families through discussions surrounding illness and treatment and foster open communication amongst members. Additionally, one must also consider the family pattern of functioning (Shell, 2007). It important to encourage participation of family members in treatment planning discussions and care decision where possible to help them feel more comfortable with the illness experience and care of their loved one (Shell, 2007; Wilkes et al., 2000). The challenge exists when family members cannot attend appointments based on geography, travel or other responsibilities. Additionally, there were challenges with NPTP where family members were unable to escort the women. Increase use of family escorts should be included in the dissemination of the study findings. Moreover, the emotional impact on family was not thoroughly explored and could be grounding for future research.

Psychological Domain

The psychological domain features a person's ability to adjust to the illness experience which includes the need for personal control and positive self-esteem (Fitch, 2009). Altered body image appeared to be directly correlated to self-image concerns and affected the women differently. Decision to proceed with breast reconstruction following a mastectomy was a very individual decision based on body image and appearance. The women who opted for reconstruction, ages ranged from 34-61 years and they were single or married. The four women that opted to have their breast/s removed and no reconstruction ages ranged from 39-77 years and were married, single or widowed. Therefore, age or marital status did not appear become a factor in the decision. In a study Fallbjork, Salander and Rassmussen (2012) the authors' explored meanings of mastectomy and reconstruction decisions in 15 women following surgery for primary breast cancer. Losing a breast was described in a variety of ways from "no big deal" to shattering their identity as a woman or losing oneself as a sexual being. The authors concluded that experiences of mastectomy or reconstruction decisions are very individual and losing a breast may be of minor or major importance to women (Fallbjork, 2012). These findings illuminate the experiences of the women in this study. The meaning of losing a breast was very individual while some women continued to be very concerned about the way they looked, others were less concerned. It is important for HCP to be attentive to the meaning of losing a breast and its effect on body image and to consider individual meaning rather than rely on preconceived notions of what women may need based on age or phase of life. These surgical decisions are very personal and support will be necessary. The rural experience did not factor in regarding surgical decisions in this study with the exception of one woman who felt rushed to make a decision to proceed to reconstruction which she later regretted.

Chemotherapy-induced alopecia and its effect on body and self-image was a noteworthy finding in this study and has implication based on living in a rural setting. Some of the women were not concerned by the hair loss. However, ten women described their hair loss as a very difficult aspect of the experience. The impact of chemotherapy-induced alopecia can have a profound social and psychological impact on individuals and can be viewed as a traumatic or a distressing experience (Hesketh, 2004; Lemieux, Maunsell & Provencher, 2008). This side-effect can cause a decrease in quality of life, lower self-esteem or lead to depression. Alopecia can often be viewed more negatively than a loss of a breast (Browall, Gaston-Johansson & Danielson, 2006; Hesketh, 2004; Lemieux et al., 2008). In addition, alopecia can be a constant reminder of illness and lead to shame, embarrassment and isolation (Bettencourt, Schlegel, Talley, Molix, 2007; Hesketh, 2004). In this study the women who were affected by this side-effect described many feelings around their hair loss including feeling “ashamed”, “embarrassed” or “tainted”.

Women also described stories where they were approached by community members or strangers in their rural settings to ask them personal questions surrounding their illness or would go out of the way to avoid situation these conversations. Social isolation is closely linked to stigma and people will often risk anonymity rather than expose themselves to others (Biordi, 2006). Stigma can result from attaching labels or stereotypes to certain individual based on appearance or physical deformity (Mann & Stuenkel, 2006). Once a person feels isolated or stigmatized based on appearance it can lead to decrease self-concept and self-esteem which further challenge adaptation to the illness experience (Mann & Stuenkel, 2006). The lack of anonymity and close-knit atmosphere in rural communities contributed to the challenges the women faced. Women talked about feeling labeled as “a cancer patient” resulting in feeling self-

conscious in public. Alopecia is an inevitable outcome of treatment for primary breast cancer so this is a problem with no easy solution. Health care providers need to be cognizant of these challenges and provide support during this difficult time. Additionally, supportive resources to help women cope with alopecia-related challenges are currently not available in many rural areas of the province. Opportunities exist to expand programs in rural settings to help support and address some of these challenges.

Feeling a loss of control was another unmet need in this domain. Loss of control is linked to powerlessness which was defined by Miller as “the perception that one lacks the capacity or authority to act to affect an outcome” (In Onega, 2006, pp. 307). Power resources such as physical strength, hope, motivation, knowledge, positive self-esteem, psychological stamina or social support can be decreased or lost in the face of illness. Depletion of these resources can lead to powerlessness and linked to physical or psychosocial limitations and serious health problems (Onega, 2006). The women described feelings powerless towards the illness, treatment outcomes, physical symptoms, health care system, need to travel or relocate, societal challenges, inability to work and increase dependence on others. White and Roberts developed a ‘Personal Control Model’ where nursing intervention can be developed to assist persons to feel more powerful (Onega, 2006; White & Roberts, 1993). The authors identify four types of control loss including physiological, cognitive, environmental and decisional. Increasing power over physiological responses would include strategies such as symptom management, comfort, guided imagery, relaxation or mediation. Cognitive control could be achieved by developing power over thoughts. Strategies such as anticipating certain sensations at times of uncertainty by reducing its mystique or reappraisal and affirming positive aspect of a situation verses fearing the worst. Environmental control loss happens when a person is unable to control

where they are and what they are experiencing. Strategies might include personalizing the environment or building relationship with a network of people within the environment including care providers. Finally, decisional control can be achieved by staying informed and looking for options that are realistic and personally relevant (White & Roberts, 1993). Nurses need to identify feelings of powerlessness in an oncology setting and design tailored interventions accordingly. The 'Personal Control Model' is a useful assessment tool to guide assessment, intervention, and teaching.

When a person achieves personal control it gives them a sense of independence and confidence in their ability to become less dependent upon others (White & Roberts, 1993). Power loss was felt by the women directly related to the illness and its associative challenges however the living rurally inflated the experience for them. The women developed unique strategies to help them cope with the illness experience such as changing one's perspective, looking for positive opportunities, distraction, maintaining wellness or a one-day-at-a-time approach. Many of these strategies are consistent with the early work of White and Roberts (1993) on powerlessness. Other studies exist in the literature have looked at coping responses and psychological adjustment following a breast cancer diagnosis (Butow et al., 2012; Compas & Luecken, 2002; Hack & Degner, 2004; Mehrabi, Hajian, Simbar, Hoshyari, & Zayeri, 2015; Silva et al., 2012). On review of these studies multiple strategies are often used. In a study by Silva and colleagues (2012) altering cognitive thinking by planning actions, accepting life-circumstances, reframing the experience by looking for positives, utilizing humor, seeking social support or looking for skills to deal with stress were strategies that were utilized by women living with breast cancer and linked to long-term psychological adjustment (Silva et al., 2012). Alternatively, in a systematic review lead by Mehragi and colleagues (2015) the authors explored

coping responses and strategies following a diagnosis of breast cancer. The authors categorized the findings according to frequently utilized coping strategies which included social support, positive reframing, reappraisal, emotional expression, avoidance and distraction (Mehragi et. al., 2015). Many of these strategies were utilized by the women to help them regain some control back into their lives. It is important for individuals to maintain control over events in their life because the need for personal control will ultimately intensify in oncology situations.

This study confirmed people will utilize a variety of ways to help them regain a sense of control over the experience. Some strategies proved to be useful and other may not have been the most effective ways to cope with the experience. Subjectively, the women who used avoidance as a primary technique were not coping as well and remained very afraid during the entire experience. As fears escalate it is common to use avoidance or distraction as a coping strategy (Thewes et al., 2016). In a quantitative study by Hack and Degner (2004) the authors' measure mood states at 6 months and 3 years following a diagnosis of breast cancer and suggest that passive acceptance, cognitive avoidance and resignation put women at a significant risk of poor long-term psychological adjustment (Hack & Degner, 2004). In a review article by Compas and Luecken (2002) the authors describes many predictors of psychological adjustment to a breast cancer diagnosis including severity of illness or symptoms, characteristics of the patient, nature of social relationships or interpersonal resources and cognitive appraisal and attributes (Compas & Luecken, 2002). The women who were not coping as effectively were required to lean heavily on social or spiritual support to help them through their illness experience. Psychological adjustment to a cancer diagnosis is a personal and unique experience. It is important for nurses to be cognizant of how a person is coping and consider the uniqueness of each individual and tailor intervention accordingly.

Personal attributes that fostered positive coping skills were illustrative in this study which included resilience, self-reliance and optimism. Developing resilience involves adopting new or enhancing previously used strategies to advance health in the face of illness (Liepert & Reutter, 2005). Strategies are behavioral or psychological in nature and influenced by environmental or personal factors. Resilience attributes can include hardiness, confidence, optimism and self-reliance (Liepert & Reutter, 2005). Interrelations between the concepts were evident in the findings and also supported by the self-efficacy theory. Self-efficacy encourages competency, promotes wellness, enhances confidence and self-esteem and ultimately fosters effective coping strategies such as increase independence and self-reliance (Bandura, 1977, 1982, 1989). Positive emotions, resilience and self-reliance are often associated with good outcomes, better emotional adjustment, decreased levels of distress and foster effective coping skills (Aspinwall & MacNamara, 2005; Carver et al., 1993; Markovitz, Schrooten, Arntz & Peters 2015; Rogers-Clark, 2002). There is also vast literature that supports self-reliance, resilience, stoicism and industrious attributes are often associated with rural living (Butow et al., 2012; DesMeules et al., 2012; Long & Weiner, 1989, 1999, 2010; Rogers-Clark, 2002). These study findings illuminate that these characteristics were positive approaches which helped the women cope with their illness experience. It is difficult to ascertain if these characteristics developed as a result of the cancer experience or were deep-rooted characteristics based on past experience. However, it is important for HCP to foster effective coping strategies, enhance self-efficacy and build on characteristic that might define rural dwellers strengths and positive supportive community's verses assuming communities are defined by their absence of specialised services.

Spiritual Domain

Spirituality and religion can be important to the well-being of people who have cancer, enabling them cope with the illness. The findings from this research suggest that individuals with cancer go through a spiritual process that is triggered by the diagnosis. This spiritual process is a unique and personal journey. The impact of a life-threatening disease can impact every aspect of a person's life and can often be associated with a crisis event when the diagnosis first arrives (Gall & Cornblat, 2002; Meraviglia, 2006). The spiritual journey became more accepted over time once the women were through the initial crisis and array of feelings and emotions. The spiritual journey was an evolving progression of renewal and re-evaluation while facing mortality, attaching meaning to the diagnosis, gaining new perspective and re-evaluating life. The spiritual journey was processed in very individual ways but was also influenced by nurturing relationships including connections to God, others, self, family or the greater community.

Most of the women talked about their own mortality as an initial reaction to the diagnosis. However, a number of women viewed the meaning of their diagnosis as yet another challenge that they had to overcome in their lives such as death or illness of a spouse, divorce, alcoholism in the family, caring for disabled children or ailing parents or living with other chronic conditions. As a result, they felt confident that they could get through yet another hurdle in their life and their own mortality was not at the forefront of their thinking. Many of these women talked about being strong or having survival skills which helped them endure challenges they faced. These findings are consistent with the work by Degner and colleagues (2003). This survey study evaluated qualitative responses from n=1012 Manitoba women with the purpose to illicit the meaning of their breast cancer based on a categorical assessment. The authors reported that 57.4 % of the respondents viewed breast cancer as a challenge based on personal

characteristics or experience they gained in their lives. As a result of the comparative process, the women talked about being strong, could serve as role models and felt fortunate to have such a good life (Degner, Hack, O'Neil, & Kristjanson, 2003). The women who approach their diagnosis with this stance came to terms with the diagnosis very quickly and as their journey evolved developed a deeper perspective on what they learned.

Other women talked about initially feeling fearful that they might die but after reflection they felt that they were not ready to give up and still had much to live for. In these situations, they quickly changed their attitude to a more positive perspective to help them cope with their fears and felt confident that the cancer would not end their lives. In a meta-synthesis conducted by Bertero and Wilmoth (2007) the authors found that awareness of one's own mortality can be a journey and challenges cancer patients to ask existentialistic questions, discover their own resilience and reorder life priorities. These women demonstrated these qualities which helped them cope with the illness experience and in essence improved their quality of life.

Other women talked about not feeling ready to die but were not afraid to die if that was the ultimate outcome. Many of these women had a strong spiritual presence, believed in God and used prayer to gain strength throughout their journey. Prayer can be described as having a conversation with God and can be positively associated with well-being and meaning (Meraviglia, 2006). Having a relationship with God is often viewed as a comforting in the face of an illness (Gall & Cornblat, 2002). Religious or spiritual belief can serve a variety of functions including: encouraging greater inner strength; increase self-faith; direct life decisions; reduce distress; increase calming feelings; enhance personal growth; creating meaning of illness; and lead to positive acceptance and hope (Gall & Cornblat, 2002). Therefore, religion can often play a significant role in offering comfort and support and provides an additional way of coping or

viewing the illness experience. The women described closeness with God and this relationship was viewed as highly important in the coping process. From this relationship the women were able to determine meaning and it gave them new insight and view of the illness.

Facing mortality and determining meaning was not without its challenges. There were a number of women who were very fearful of the outcome of dying from their illness. They talked mostly about the fear of leaving their families without a wife, mother or grandmother. These women viewed their cancer as a punishment, invasion or violation of their bodies and found it more difficult to attach a positive meaning to the diagnosis. Degner and colleagues (2003) reported that only 6 % of the women who respond to their survey study attached irreparable loss as a meaning of their breast cancer which led to powerlessness and loss of control and fear of recurrence or concerns about dying resulted (Degner, et al., 2003). It is difficult to ascertain why these women had a much more difficult time coping with their ongoing fears as compared to the other women but it resulted in having to draw heavily on others for emotional or spiritual support before spiritual wellness could be achieved.

Ultimately the search for meaning evolved into gaining a new perspective and re-evaluating important aspects in the lives of the women. Many studies in the literature support that spiritual growth and wellness following a cancer diagnosis frequently involves this re-evaluation process (Bertero & Wilmoth, 2007; Costa Vargens & Bertero 2012; Degner et al. 2003; Gall & Cornblat, 2002; Schulz et al., 2008; Swinton, et al., 2011). In a study by Schultz and colleagues (2008) the authors examined the role of spirituality in coping with cancer. From their qualitative analysis they propose five behaviors to enhance cancer coping, improve quality of life and form the basis to spiritual wellness which include: developing a closer relationship with God or seeking God's presence; developing deep bonds with family, friends, community

members or other cancer survivors; developing self-awareness including self-understanding, self-honesty or self-love; releasing negative connections to people that may have been less positive; and developing a greater connection to the world by helping others and giving back (Schulz et al., 2008).

In other studies, affirmation of the value of life and re-evaluating life priorities helps people living with cancer give their life purpose (Bertero & Wilmoth, 2007; Costa Vargens & Bertero, 2012; Degner et al., 2003). The findings in this study align with the spiritual concepts and road to spiritual wellness featured in the literature. Many of the women talked these important concepts such as changes in relationships, self-awareness and respect, giving back to others, making every day count, making important memories as some of the descriptors in the interviews. Concepts such as finding meaning, gaining perspective, re-evaluating life and new beginnings proved to influence wellbeing in many domains in the framework. Spiritual and social wellbeing, emotional and psychological adjustment to the illness experience helped the women adapt and cope with the overall experience. Positive spiritual adaptation was an important finding in this study and was experienced many of the women. However, long-term adjustment and survivorship from a holistic perspective was beyond the scope of the study.

Discussion Summary

In summary, addressing the supportive care needs of individuals affected by illness is an essential activity for nurses. Many unmet needs exist in the study findings related to the rural experience and the framework provided a holistic overview to assess what those needs were. Many interrelationships between the domains in the framework exist therefore challenges in one domain indirectly affected functioning in another domain. Additionally, there were many positive findings in the study that were also featured. Therefore, the framework became an

overwhelmingly useful tool to provide a full constellation of needs in each of the domains so that the meaning of participants lived experience could be described, interpreted and fully discussed. Additionally, the findings in this study were strongly supported by the current and past literature and therefore form the basis to develop programmatic approaches, tailored individual and shared intervention to improve cancer services in the province of Manitoba.

Study Limitations and Strengths

There are a number of limitations that warrant consideration. People who live in remote areas of the province were not captured in this study and it could be assumed that the challenges that they face would be quite different. Additionally, the male cancer population or people from different ethnic backgrounds or culture would not be illustrative from these study findings. Recruiting cancer patients from different cultural and ethnic backgrounds or predominantly male cancers would provide a more heterogeneous image of the rural cancer experience. Another study limitation worth considering is the findings did not capture other populations such as long-term cancer survivors, advanced or palliative cancer diagnosis or the family care-giver experience. Therefore, generalizing the findings in this context could not be considered. These indications provide a path for future research to develop a greater depth of the challenges or positive features related to rural living in these populations

There are a number of strengths from the study findings that should also be considered. The findings generated from this research study provide rich descriptive insight into the lived experience of rural people living with cancer in the province. Only people who have lived experience can provide the true essence of what the experience entails. Moreover, the study findings were strongly supported by the past and current literature. There is dearth of literature based on the Manitoba population that are specific to our health care services in this province,

therefore the study findings and recommendations will prove to be a valuable for HCP practicing in health care settings in Manitoba in both urban and rural sites to inform practice. Additionally, the study will also be of interest to nurses working in oncology settings nationally as similar models of care and geographic isolation in cancer populations is a noted challenge in our Canadian population. Practical recommendations for practice, education and research will provide insight on how we can create positive change for rural people living in Manitoba faced with a cancer diagnosis. The study findings will be disseminated at a provincial and national level through publications and presentations.

Chapter Summary

This chapter highlighted a discussion of the findings according to each domain in the supportive care framework which was supported by the scholarly literature. Both the positive and challenging features of living in rural settings were highlighted in the discussion of the findings. Additionally, current rural health care and supportive services and upcoming initiatives were also threaded throughout the discussion which will be utilized to build on service recommendations. Study limitations and strengths were identified which provides future implications for research and dissemination of study findings. Chapter eight will provide a summary of the recommendations put forward from the study findings.

Chapter 8: Recommendations and Conclusions

Chapter eight presents an overview of the recommendations that will be represented from this study. These recommendations are grounded in the rich descriptions and suggestions from the women who participated in the study that were compiled from the interviews, presented in Chapter 6 and discussed in Chapter 7. Recommendations for practice, education and research provide the foundation of the content in this chapter.

Recommendations

Recommendations for Practice

The primary goals of this research study was to provide rich interpretive descriptions of the supportive care experiences of rural women living with IBC through all the phases of illness from diagnosis to end of treatment. Another goal of this research study was to develop practical recommendations on how to improve supportive care services for women living with breast cancer in the province. With this in mind recommendations for practice is three-fold including: implications for nursing practice, interdisciplinary practice and service delivery.

Implications for nursing practice. Nurses will work with cancer patients from rural areas in a variety of urban and rural settings. A generalist nurse will work with oncology patients in variety of settings including surgical or medical units, in primary care clinics or emergencies. A specialized oncology nurse or advanced practice oncology nurses cares for patients in specialized centers such as CCMB, CCP or specialized in-patient units in urban or rural centers where the primary focus is cancer delivery (CANO, 2001). Additionally, nurse practitioners are positioned in urban and rural primary health care settings but may not have expertise in oncology-related theory and practice. All nurses need to be aware of specific challenges related living with cancer from rural areas of the province. The findings from this study bring up many

pragmatic recommendations for nursing practice. These recommendations have been categorized according to the nine standards of practice developed by CANO (CANO, 2001).

Individualized and holistic care. The supportive care framework provides a holistic approach to assessment, intervention and service delivery. It is important for nurses to assess individual experiences but have awareness of the shared challenges that rural people face based on travel, relocation, isolation from family, additional costs or access to services. Additionally, consideration of the positive aspects of living rurally should also be considered. Tools are available to assist in facilitating holistic supportive care assessment which will provide the basis for the development of tailored intervention and a plan that fits the individual's preferences, beliefs and needs of people living with cancer in our province (CANO, 2001; Fitch, 2006).

Family centered care. Family centered care is a philosophic approach to service delivery in all settings (CANO, 2001). An important finding in this study was the impact family had on the unmet needs that the women faced. The women relied heavily on family to deal with the additional burden related to living rurally such as travel, meeting practical and physical demands of illness or providing the additional emotional support that they required. Moreover, social isolation occurred at many levels including time to relocate. It is important that nurses understand the implication family has on the care of a person living with cancer and family inclusion is a vital component in every aspect of care. Inclusion of family should be considered during relocation and medical visits to an urban center whenever possible.

Self determination and decision-making. Individuals with cancer have the right to self determination by choosing to take or not to take action in one's life. They also have the right to access information, make decision surrounding their health care or choose not to participate (CANO, 2001). There were a number of challenges surrounding receiving and retaining the

appropriate information at the beginning stages of illness noted in this study. Nurses are positioned to provide up-to-date and evidenced-based education on areas such as pain and symptom management, managing oncology emergencies or complex treatment plans therefore nursing involvement early in the journey is imperative to provide the informational support people will require. It is also important for nurses to be aware of the additional challenges rural women face and take the time to ensure they are informed in a way that meets their needs.

Navigating the system. Individuals with cancer and their families are entitled to have assistance to navigate the complex web of cancer system and services. Coordinating efforts to ensure the person has the practical, physical, psychosocial, educational support they need to foster effective coping strategies and maximize healthy functioning is imperative (CANO, 2001). Fragmentation and coordination of services from primary care to cancer care and back to primary care was an important finding in the study. Rural people have the additional burden of limited support and services in their rural setting therefore patient navigation is a vital service at initial diagnosis and throughout the illness trajectory to ensure the patient has access to information and resources they need to navigate the system. Nurses are positioned to promote and advocate for this vital service and ensure it is well utilized in our rural oncology population.

Coordinated, continuous care. Coordination of care among providers throughout the treatment trajectory is essential for people living with cancer (CANO, 2001). Concepts such as ambulatory oncology, early discharge from acute settings, disease and treatment specific models of care in oncology and follow up primary care services can make the cancer experience that much more confusing for patients and their families. Nurses practicing in both cancer and non-cancer settings are positioned to be the link to provide continuous and coordinated care considering the complex rural issues that were presented in the findings of the research study.

Supportive, therapeutic relationships. Supportive, knowledgeable, caring and therapeutic relationships with nursing were demonstrated in the study findings. From a rural perspective it also became apparent that close relationships with the nurses in CCP and those who used navigation services were highly valued. Building on these services to ensure nursing is supported and have the resources and infrastructure to continue to provide the exceptional work they do is an important implication for practice.

Evidence-based care. Individuals with cancer should have care that is based on best practice and available evidence. The experience of cancer is complex and requires professionals who have up-to-date knowledge on cancer theory and practice (CANO, 2001). It is important that nurses have relevant oncology-related resources available to draw on when complex situations arise. This is especially important for nurses who are working in rural or isolated communities with limited resources and limited expertise in oncology-related problems.

Professional care. Personal values and beliefs exist amongst HCP. Ethical principles are often challenges in the face of caring for persons with cancer (CANO, 2001). Although, it did not occur in this study, ethical issues surrounding treatment decisions related to the burden of travel may arise in our vulnerable rural populations. Additionally, rural nurses are in a position where they may have personal or community connections to the people in their care. These are important implications for nurses to consider when caring for people living with cancer. However, further research on these challenging issues is warranted.

Leadership. Nursing are positioned to provide professional leadership at many levels of the health care system. Strong and effective nursing leadership is essential to promote change at organizational and policy level to facilitate improvement in system and ultimately improve care at the clinical level (CANO, 2001). Nursing leadership is essential to ensure positive change is

evoked for rural people living with cancer. The findings of this study illuminate many areas where change can and should happen. It will take a collaborative effort to drive the vision for improvement in support and service through the words of the women who participated in this study.

Implications for interdisciplinary practice. The women spoke about who was missing from the health care team and how they would have benefited from the services of multiple disciplines. Availability of interprofessional services is widespread at CCMB and Brandon but limited and fragmented in rural health care settings across the province. The benefits of interprofessional practice delivery models were highlighted in the discussion of the findings. With the proposed implementation of MyHT in rural primary care opportunities exist to find ways to decrease the barriers of interprofessional practice from an individual, practice and system level and optimize the use and effectiveness of primary health care teams in collaboration with oncology teams in rural settings (Conference Board of Canada, 2012; Peachy et. al., 2017). Opportunities exist to build partnerships with other HCP in rural settings to assist in managing complex oncology problems and supportive care needs of individuals living with cancer. Maximizing the skills and expertise across discipline provides opportunity for decrease travel to urban centers for care and promotes more efficient and cost effective delivery of health services (Conference Board of Canada, 2012; Peachy et. al., 2017; WRHA, n.d. c). Health care providers need to be aware of benefits and barriers of interprofessional collaboration to benefit patient/family-centered care in rural oncology settings.

Implications for service delivery. There are many recommendations that have resulted from the study findings that should be considered to enhance service delivery in rural areas.

These recommendations have the opportunity to prevent delay in diagnosis, improve wait times, decrease travel demands and enhance support and services.

1. Improved diagnostics in rural settings.
2. Specialist site clinic visits in rural areas.
3. Encourage recording of sessions with specialist.
4. Increased awareness and promotion of navigation support and services.
5. Increased utilization of navigational services at initial diagnosis.
6. Enhancement of rural UPCON services and communication between primary care and CCMB.
7. Increase use of interdisciplinary health care team in rural areas.
8. Increase use of telehealth services.
9. Improved emergency care in rural settings.
10. Increase use of family escorts to enhance family care giving.
11. Consideration to discharge times and appointment schedules around travel.
12. Promotion and increase awareness of socially directed supportive services such as meal service, driver programs or educational or peer support programming.
13. Encourage community participation to advocate and facilitate socially-directed supportive services.
14. Expansion of supportive relocation facilities in urban settings
15. Increase peer support programs into rural health services.
16. Improved aesthetics and private spaces in rural CCP.

Recommendations for Education

There are many implications for education at an undergraduate level that warrant consideration. First, opportunities exist to enhance oncology content in undergraduate nursing curriculum in the nursing programs in Manitoba. Nurses who practice in generalist settings should have the opportunity to feel prepared or know what resources are available to manage oncology-related challenges at all phases of the treatment trajectory. Second, interprofessional education (IPE) is vital content in an undergraduate curriculum programs across all disciplines. It is important for nursing faculty to thread IPE into many of the courses throughout nursing programs so we prepared nurses to be collaborative practitioners in the face of complex health issues such as cancer. Third, rural nursing is a very unique practice. Rural nurses need to be prepared for variability, complexity and have a wide range of skills and knowledge. They also need to be prepared to practice in situation where there may have limited supports and resources (MacKinnon, 2014). Undergraduate nursing faculty should consider providing advanced skills and knowledge to students who intend to practice in rural settings. Opportunities for rural electives or threading rural content across the curriculums could be considered.

Implications for education at a practice level also exist. Nurse educators, clinical nurse specialists and nurse administrators need to ensure continuing education opportunities in oncology exist for practicing nurses in both urban and rural settings. Additionally, HCP working in primary care settings could benefit from educational opportunities in cancer care through the UPCON program or stream-lined sessions at CCMB. It is also important to ensure oncology resources are available for practitioners working in rural settings. Finally, programs such as UPCON and Urgent Cancer Care helpline are important resources that should be enhanced to support HCP practicing in rural settings in the face of complex oncology care. Engaging in

dialogue with nurse educators at CCMB to help enhance opportunities for oncology education at a provincial practice level would be an important consideration.

Recommendations for Research

There were many questions posed throughout the discussion of findings that provide grounding for future research. The following form the basis to pose specific research questions that have the potential to build on the findings in this study.

1. Explore experiences of family care-givers in a rural cancer context.
2. Explore experiences of people with cancer from remote areas of the province.
3. Explore experiences of rural cancer patients across cultures.
4. Ethnographic study of the rural culture in CCP.
6. Explore the supportive care needs of male cancer patients living in rural settings.
7. Explore the lived experience in rural palliative care settings.
8. Explore the experiences of rural long-term cancer survivors.
9. Examine treatment decisions based on burden of travel or financial implications.

Chapter Summary

This interpretive descriptive qualitative study has featured the supportive care needs of rural women living with IBC from diagnosis to the end of the treatment phase of illness.

Different challenges exist in each phase of the journey but as the women reached the end of the treatment phase of illness and had the opportunity to reflect they mostly felt that their life and outlook had changed positively as a result of the experience. The essence of the experience from the women has provided a rich description of the rural cancer experience and insightful recommendations that conclude this final chapter.

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List of Appendices

Appendix A: List of Abbreviations

Appendix B: List of Medical Definitions

Appendix C: Supportive Care Framework

Appendix D: Chemotherapy Regimens

Appendix E: Rural CCP Sites

Appendix F: Recruitment Poster

Appendix G: Recruitment Information

Appendix H: Introduction Letter

Appendix I: Telephone Script

Appendix J: Demographic Questionnaire

Appendix K: Additional Demographic Guide

Appendix L: Interview Guide

Appendix M: Second Interview Guide

Appendix N: Ethics Approvals

Appendix O: Consent Form

Appendix A

List of Abbreviations

Full Title	Abbreviation
Activities of Daily Living	ADL
British Columbia	BC
Canadian Cancer Society	CCS
CancerCare Manitoba	CCMB
Census Metropolitan Area	CMA
Community Cancer Program	CCP
Computerized Tomography	CT
Central Venous Line	CVL
Employment Income Assistance	EIA
Family Physicians in Oncology	FPO
First Nation and Inuit Health Branch	FNHIB
Health Care Providers	HCP
Instrumental Activities of Daily Living	IADL
Invasive Breast Cancer	IBC
Keewatin Tribal Council	KTC
Magnetic Resonance Imaging	MRI
Manitoba	MB
My Health Care Teams	MyHT
Northern Patient Transport Program	NPTP
Nursing Research Ethics Board	NREB
Regional Health Authorities <ul style="list-style-type: none"> • Northern Health Region • Prairie Mountain Health • Southern Health Sante Sud • Interlake Eastern Health Region • Winnipeg Regional Health Authority 	RHA NHR PMH SHSS IEHR WRHA
Research Resource Impact Committee	RRIC
Uniting Primary Care and Oncology	UPCON

Appendix B

List of Medical Definitions

Abdominal flaps: Breast reconstruction procedure whereby muscle, skin, fat and blood vessels are transplanted from the abdominal cavity to the chest wall to re-create the shape of the removed breast (National Cancer Institute, n.d.).

Adjuvant therapy: Additional cancer therapy such as chemotherapy, radiation, biologic therapy or hormone treatment that is delivered after primary therapy to reduce the risk that cancer could reoccur (National Cancer Institute, n.d.).

Alopecia: Complete total body hair loss as a result of chemotherapy treatments (Langhorne et al., 2007).

Aromatase inhibitors: Pharmacologic classification of drugs representing first-line hormone treatment for hormone receptor positive post-menopausal women with breast cancer (Deglin & Vallerand, 2003).

Bone marrow suppression: Depletion of granulocytes (white blood cells), erythrocytes (red blood cells) and thrombocytes (platelets) usually as a result of the toxic side effects of chemotherapy (Langhorne et al., 2007).

Breast Augmentation: A surgical procedure following breast reconstruction where the reduction of the remaining breast may be required to achieve symmetry (Langhorne et al., 2007).

Cardiomyopathy: A heart muscle disease which affects the structural or functional ability of the myocardium. In the case of malignancy this would be a secondary condition caused by the cardiotoxic effects of chemotherapy agents such as Epirubicin used in breast cancer adjuvant therapy (Lewis et al., 2004)

Central Venous Line: A device that is surgically implanted into the larger venous system and used to administer agents such as chemotherapy (Langhorne et al., 2007).

Cellulitis: A serious bacterial infection of the skin associated with pain, redness and tenderness (Langhorne et al., 2007).

Extravasation: An unintentional leakage of intravenous drug into tissue usually prevented by insertion of a CVL for patients undergoing chemotherapy (Langhorne et al., 2007).

Febrile Neutropenia: Oncology emergency characterized by a high fever and low white blood cell count associated with disease or chemotherapy-induced toxicity (Langhorne et al., 2007).

Lymphedema: Swelling of the affected limb related to obstruction, removal or radiation of lymph nodes (Langhorne et al., 2007)

Mucositis: Inflammation of the oral mucous member as a potential side effect of chemotherapy (Langhorne et al., 2007).

Neoadjuvant: A main treatment such as chemotherapy or radiation is delivered to shrink the size of the tumor prior to surgical intervention (Langhorne et al., 2007).

Neupogen: Colony-stimulating agent administered subcutaneous to prevent febrile neutropenia and infection in cancer patients receiving bone marrow suppressive chemotherapy agents (Deglin & Vallerand, 2003).

Neutropenia: Decrease in circulating neutrophils which represent 85% circulating white bloods cells with the direct role of fighting infections (Langhorne et al., 2007).

Oral Thrush: Fungal infection infiltrating the oral mucosa, tongue and throat. Oral thrush commonly occurs in cancer patients receiving chemotherapy and has the ability to spread throughout the gastric system (Langhorne et al., 2007).

Osteoporosis: A degenerative, progressive disease that is characterized by low bone mass, structural deterioration of the bone tissue leading to bone fragility. In the case of breast cancer this can result from long term use of hormone therapy (Langhorne et al., 2004; Lewis et al., 2004).

Palmar Plantar Erythrodysesthesia: A dermatologic chemotherapy-induced toxicity characterized by pain, redness, scaling and erythema on pressure bearing areas of the palms of the hands and soles of the feet (BC Cancer Agency, 2014).

Peripheral Neuropathy: Damage to the peripheral nerves in the hands and feet as a direct result to chemotherapy agents caused numbness, tingling and pain (Langhorne et al., 2007).

Phantom Pain: A painful stimuli that comes from an area were a body part was removed. The removed breast could result in a painful sensation that may be psychological or neurological in nature (Lewis et al., 2010).

Pneumonitis: An inflammation of the lung caused by radiotherapy need the lung fields (Langhorne et al., 2007).

Pulmonary Fibrosis: Scar tissue that develops in the connective tissue of the lungs manifested by significant respiratory symptoms. In the case on a malignancy it can be caused by certain cytotoxic agents or radiotherapy involving areas near around the lung fields (Langhorne et al., 2004; Lewis et al., 2004).

Appendix C

Supportive Care Framework

Domains	Operational Definitions	Examples
Physical	“Needs related to physical comfort and freedom from pain, optimum nutrition, ability to carry out one’s usual day to day functions” (pg. 18).	Pain Nausea Shortness of breath Weight changes Anorexia
Informational	“Needs related to information to reduce confusion, anxiety and fear; to inform the person’s or family’s decision-making; and to assist in skill acquisition” (pg. 18).	Side effects Drugs Treatment regimens Care processes and service Help with decision making
Social	“Needs related to family relationships, community acceptance and involvement in relationships” (pg. 19).	Roles Communication Telling people about the diagnosis
Practical	“Needs related to direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person” (pg. 19)	Homemaking Shopping Child care Transportation Financial issues
Emotional	“Needs for a sense of comfort, belonging, understanding and reassurance in times of stress and understanding” (pg. 18).	Grief Uncertainty Fear Anxiety
Psychological	“Needs related to ability cope with the illness experience and its associative consequences, including the need for optimal personal control and the need to experience positive self-esteem” (pg. 19).	Loss Self image Depression Fear of recurrence Body image
Spiritual	“Needs related to the meaning and purpose in life” (pg. 19).	Spiritual distress Existential Despair Examining personal values Religious beliefs

Adapted from: Fitch (2009, pg. 18-19)

Appendix D

Chemotherapy Regimens

The following are standard chemotherapy regimens for invasive breast cancer. Trantuzumab (Hercepten) therapy is indicated based on specific biologic indicators (HER2) that test positive at diagnosis (BC Cancer, 2014; CCON, 2016).

Low Risk Breast Cancer

TC+/- TRAS: Docetaxal/Cyclophosphamide +/-Transtuzumab

- 4 cycles Intravenous (IV) every 21 days
- 4 cycles IV every 21 days followed by 18 months of Trantuzumab therapy

Intermediate Risk Breast Cancer

FEC/D+/- TRAS: Flurouracil/Epirubicin/Cyclophosphamide/Docetaxal+/-Transtuzumab

- 3 cycles FEC followed by 3 cycles D every 21 days
- 3 cycles FEC followed by 3 cycles D every 21 days followed by 18 months of Trantuzumab therapy

High Risk Breast Cancer

Neoadjuvant FEC 4/D4 +/- TRAS: Flurouracil/Epirubicin/Cyclophosphamide/Docetaxal+/-Transtuzumab

- 4 cycles FEC followed by 4 cycles D every 21 days
- 4 cycles FEC followed by 4 cycles D every 21 days followed by 18 months of Trantuzumab therapy

(Adapted from: CCON, 2016)

Appendix E

Community Cancer Programs (CCP) in Manitoba

Boundary Trails CCP	Hamiota CCP
Western Manitoba Cancer Center (Brandon)	Neepawa CCP
Dauphin CCP	Pinawa CCP
Deloraine CCP	Portage CCP
Flin Flon CCP	Russell CCP
Gimli CCP	Selkirk CCP
Swan River CCP	The Pas CCP
Thompson CCP	Steinbach CCP

Adapted from: CancerCare Manitoba (2000)

Appendix F
Recruitment Poster

INVITATION TO PARTICIPATE IN A RESEARCH STUDY



Strength
Courage
Hope

IF YOU HAVE BREAST CANCER AND LIVE IN A RURAL AREA WE WANT TO HEAR FROM YOU?
OUR GOAL IS TO IMPROVE PROGRAMS AND SUPPORTIVE SERVICES FOR RURAL WOMEN LIVING WITH BREAST CANCER IN OUR PROVINCE

Who can become involved: Diagnosis of Invasive Breast Cancer, completed treatment including surgery, chemotherapy and radiation, live in a rural regional health authority in Manitoba.

What to expect: Two recorded interviews about your cancer journey in a setting of your choosing.

PARTICIPATION IN THIS STUDY IS COMPLETELY VOLUNTARY AND YOUR PERSONAL INFORMATION WILL BE KEPT CONFIDENTIAL

For more information please contact your primary clinic nurse or health care provider.

Primary investigator: Joanne Loughery RN BN, Master of Nursing Student

This study has been approved by the Education Nursing Research Ethics Board at the University of Manitoba. If you have concerns or questions you may contact Human Ethics Coordinator, Maggie Brown

Appendix G

Study Information for Recruitment Sites

Project Title

Supportive Care Experiences of Rural Women Living with Breast Cancer: An Interpretative Descriptive Qualitative Study

Research Background

Living with breast cancer and associative challenges is a difficult experience regardless of geographic location. Multi-modality treatment regimens will be implemented which are invasive, complex and time-consuming. Supportive care describes the needs of persons living with cancer from multiple domains. These include physical, informational, social, practical, spiritual, psychological and emotional domains. When cancer strikes, geographic location can become a significant barrier to care related to fragmentation of oncology services a rural setting often requiring re-location to an urban setting for care.

The primary purpose of this qualitative study is to arrive at an increased understanding of the supportive care experiences of adult women requiring treatment for invasive breast cancer and who reside in rural Manitoba. The objectives guiding this study are:

1. To describe the supportive care experiences of women living with invasive breast cancer who require multi-modality treatment regimens and reside in rural Manitoba.
2. To explore how the supportive care experiences change from detection to the end of the treatment phase of illness specific to living in a rural setting.
3. To identify recommendations on how to improve the supportive care experiences of rural women living with breast cancer in the province.

Participant Sample

For this study, approximately five participants from each of the rural Regional Health Authorities will be interviewed. It is anticipated it will take approximately six month to complete this work.

Inclusion Criteria

- 1) Able to speak, read and write in English
- 2) No cognitive impairment
- 3) A diagnosis of invasive breast cancer, Stage II or III
- 4) Adult women
- 5) Completed multi-modality treatment regimens including surgery, systemic therapy and radiation within the last three years
- 6) Reside in rural Manitoba outside the CMA of Winnipeg

Exclusion Criteria

- 1) Stage I or IV disease
- 2) Live in the CMA of Winnipeg or surrounding municipalities
- 3) Relapsed or progressive illness.

Recruitment Procedures

Potential participants for this study will not be approached by the investigator until they indicate that they are interested in learning more about the study. An invitation to participate must be provided by an individual who has no involvement with the study. I am asking for assistance from front line health care professionals who care for breast cancer patients to act as intermediaries for this study.

Once you have identified an individual who meets the outlined criteria, please provide them with the invitation to participate letter.

If the individual is interested in participating:

- 1) Ask them to contact me directly, contact information provided or
- 2) Upon verbal permission to release their contact information, please notify me of their name and number and I will contact them directly.

If they agree to participate then a formal consent process will take place and an appropriate meeting date will be set. It is important that all potential participants are aware that their participation is entirely voluntary and their care will not be affected in any way by their willingness or refusal to participate. Ethics guidelines, privacy and confidentiality will be maintained.

The information gained from this study will be used to inform both existing and new services and programs that are directed at helping rural Manitobans living with breast cancer in our province. The findings from this study will be disseminated to the CancerCare community in MB. Thank-you for your assistance and please do not hesitate to contact me directly with any question or the need for clarification.

Sincerely,

Joanne Loughery RN, BN
Master of Nursing Student
University of Manitoba

Thesis Advisor
Dr. Roberta Woodgate RN, PhD
Canadian Institutes of Health Research Applied Chair in Reproductive, Child and Youth Health
Services and Policy Research
Professor, Child Health and Illness
Faculty of Health Sciences, College of Nursing

Appendix H

Recruitment Letter

Dear (potential participant):

My name is Joanne Loughery, and I am a nursing educator at Red River College and a student in the Master of Nursing program at the University of Manitoba. To complete my program, I am doing a research project to learn more about the experiences and supportive care needs of women living with breast cancer who live in rural areas of our province. A cancer diagnosis is a difficult experience regardless of geographic location. It is important understand additional challenges from the perspective and experiences of rural women that have recently completed breast cancer treatment and live in rural areas of our province.

Dr. Roberta Woodgate, Thesis Advisor, Faculty of Health Sciences, University of Manitoba is supervising the research study. This study has been approved by the Education and Nursing Research Board at the University of Manitoba, Research Ethics Board at CancerCare MB and in each Rural Regional Health Authority.

To fulfill the purpose of the research, my aim is to interview approximately 20 women different regions of the province. I am seeking approximately $n=5$ women per rural regional health authority. With your permission, I would like to interview you in a setting of your choice. The interview will take approximately one to two hours to complete.

In order to confirm the information from the first interview and for you to offer any further information, a second interview will take place. This interview will take approximately 30 minutes to one hour and can be done in person or on the phone. If you wish, you may decline the second interview. The interviews will be digitally recorded. Only my advisor and I will have access to this personal information.

Once all the interviews are completed, the information will be compiled and summarized. It will be shared in a publication and with the professionals who care for individuals living with cancer in this province. The information gained from this study will be used to inform both existing and new services and programs that are directed at helping rural women living with breast cancer in our province.

All identifying personal and demographic data will remain confidential and never revealed to anyone, including your health care team or in future publications or professional presentations. If you wish, you will have the opportunity to receive a summary of the study.

Please inform the person who gave you this information whether you would or would not like to hear more about this study. You can either contact me directly or you can give permission to your nurse to release your contact information to me. Over the phone, I will explain the study to you in detail. Participation in this study is completely voluntary. There will be no consequences if you decide not to participate. If you wish to participate an interview will be arranged at a time and

setting of your choice. You may contact me at any time if you have questions or you may also contact Dr Roberta Woodgate.

Thank-you for your time and consideration.

Sincerely,

Joanne Loughery RN, BN
Master of Nursing Student
University of Manitoba

Dr. Roberta L. Woodgate
Canadian Institutes of Health Research Applied Chair in Reproductive, Child and Youth Health
Services and Policy Research
Professor, Child Health and Illness
Faculty of Health Sciences, College of Nursing
University of Manitoba

Appendix I

Telephone Script

Hello _____

My name is Joanne Loughery, and I am a Master of Nursing student at the University of Manitoba. I have been told by _____ from _____ that you have received an introduction letter about a study I am doing and are interested in hearing more about it.

To complete my program, I am doing a research project to learn more about the experiences and supportive care needs of women living with breast cancer who live in rural areas of our province. A cancer diagnosis is a difficult experience regardless of geographic location. It is important understand additional challenges from the perspective and experiences of rural women that have recently completed breast cancer treatment and live in rural areas of our province.

In this study, I will be conducting interviews with individual women following completion of their breast cancer treatments. The interview will take approximately one to two hours. It will be in a place of your choosing that is comfortable and private. The interviews will be tape recorded so that I do not miss any important information. A second interview will be of benefit to cover any material that may have been missed in the first interview and ensure that I have accurately captured your correct information.

All interviews will be typed and read by my advisor and I. We are the only people who will have access to this material. Common thoughts and themes from all the participants will be sorted, compiled and summarized. I will be the only person who knows your identity. All participants will be given a code number to ensure confidentiality. No-one will ever know you participated in this study or will be able to determine where you live. All materials will be stored in a secure place until they are no longer needed and subsequently destroyed.

This information will be written up to fulfill the requirements for my thesis. No identifying data will be in the thesis information or any further publications or presentations. Once everything is completed you will have the opportunity to receive a copy of the summary of this study.

If you agree to participate, you may withdraw from the study at anytime without consequence nor will you be required to participate in a second interview. You may also choose not to answer any questions or stop the interview at any time.

Do you have any questions regarding this study? Would you be willing to participate?

No: Thank-you for your time and consideration of this study.

I would like to think about it: Thank-you for your consideration. When can I call you back to find out your final decision?

Yes: Thank-you for your participation. When would be a good time to set up the interview? Where would you like it to take place?

During the first interview, I will review a consent form with you. This is done to ensure you understand details of the study and agree to participate. I will be also asking you to fill in a short form so I can know a few more details about you.

It will be helpful to think about the cancer experience as it relates to living in a rural setting. I will be asking you questions about your cancer journey from the time you were diagnosed to the end of your treatments. My goal will be to assist women living with breast cancer from rural areas. If you have ideas or suggestions on how we can improve service that will be of benefit as well.

The confirmed date and time we will be meetings is _____. Thank-you for your time and I am looking forward to meeting you.

Appendix J

Demographic Questionnaire

ID#: _____

Date: _____

Information on this form will provide background information about you and your breast cancer treatment. All this information will remain confidential.

1. Age _____

2. Marital Status _____

3. How many people live in your home? _____

Include Relationship, Age, Sex, Are they able to assist? Why or Why not?

4. Where do you live? _____

House _____ Apartment _____ Other _____

5. Approximately how many kilometers are you from Winnipeg? Brandon?

6. Highest Level of Education _____

Do you work? _____ Are you retired? _____

Where are you employed? _____

Part-time _____ Full-time _____

Temporary _____

Do you have access to a disability income benefit?

7. What is your ethnic background? _____

8. Do you know the stage of your cancer?

9. What treatments have you received and where?

Surgery: Location _____

Lumpectomy_____ Modified Radical Mastectomy_____

Radical Mastectomy_____ Reconstruction _____

Chemotherapy: Location _____

Number of cycles of treatment

How often

Length of time from start to finish

Radiation: Location _____

Number of radiation treatment

Were you given advanced warning when the radiation treatments were to start?

10. Do you have any other medical conditions other than breast cancer?

Appendix K

Treatment Documentation (Second Interview)

Confirmation of Dates and Specifics related to treatment

Detection: Confirm

Date _____

Date of Diagnosis:

Stage:

Surgery Date:

Location of Surgery:

Chemotherapy/Biologic Therapy:

Date:

Location:

Radiotherapy Date:

Location:

Hormone Treatment:

Date Started:

Appendix L

Interview Guide

Introduction to this interview: I would like to learn more about your journey with breast cancer. I would like for you to share your experiences from the time you were diagnosed to the end of treatment. To help tell your story I will ask you a series of questions. I will ask you to share your experiences that affect the basic aspects of your life with all your treatments that you had and the challenges it placed on your life. I would like you to share your rural experience in this interview. One of the primary goals of this study is to find ways to improve the lives of women living with this illness from rural MB. During this interview I would like to explore the challenges and opportunities as it relates to your personal experience. As well, any suggestions you may have about services that were helpful and any suggestions you can provide to assist in the development of important programs for rural women living with breast cancer.

NOTE: PROBES WILL ONLY BE ASKED AS NECESSARY. THEY ARE MEANT TO STIMULATE DISSUSION.

1) Can you please tell me a little about yourself and family life before your diagnosis of breast cancer?

Probes:

- What was day-to-day life for you and your family?
- What were your plans for the future?
- Have you always lived in a rural setting?
- What does living rurally mean to you?
- What are your sources of strength in this community?
- How were you managing on a day-to-day basis?

2) Can you tell me what it was like when you became ill and its impact on your life?

Probes:

- Who made the diagnosis and how was it found?
- Did you have to go to Winnipeg or another center when it was first discovered?
- Did you feel comfortable with the care you had from your health care provider in your home town?
- Can you share your experiences from the time your cancer was first found to when you were able to see a cancer specialist
- How did this new diagnosis affect you?
- How did this diagnosis affect your family?
- How did this diagnosis affect your social life?
- What were the implications related to your work?
- What were some of your initial concerns or fears with your new diagnosis?

- What additional services or supports would have been beneficial during this time?
- Were there any day to day adjustments that you had to make when you were first diagnosed with breast cancer?
- Are there any implications that should be considered, living in a rural area with a new diagnosis of breast cancer?

3) Can you walk me through your cancer journey and different treatments that you have incurred?

The interviewer will walk the participant through the seven domains of the Supportive Care Framework and ask the participant to talk about each domain and how each domain was experienced depending on the stage of the cancer journey.

Probes:

- Did you feel well informed about your treatment options
- If you were required to re-locate, for how long and can you share the details of this experience? Where did you stay?
- Can you describe some of your physical symptoms during your treatments?
- Did travel aggravate any of these symptoms?
- Can you describe some of your feelings emotionally?
- Who was your primary source of support during this time?
- Do you feel you had access to supports in your rural setting to help you during this time?
- How did this experience affect your family?
- How did this experience affect your day-to-day life?
- Did you have to incur any additional expenses related to travel to an urban setting?

4) Can you talk about the barriers and challenges that you experienced during your treatments and how living rurally has impacted?

The interviewer will walk the participant through the seven domains of the Supportive Care Framework and ask the participant to talk about each domain and the type of barriers and challenges experienced related to each domain.

Probes:

- Did you have any major problems during your treatments that required medical attention or hospitalization? Where did you receive the care? Did you feel comfortable with the care you received?
- Did you ever have to stay in Winnipeg for an extended period of time during any of your treatments? Where did you stay? How long? Can you share this experience with me?
- What were the additional costs that you incurred during this time directly related to living rurally?
- Can you tell me how living rurally has impacted your experience with cancer?

- How has this overall experience affected your family? Were there any changes in roles within your family because of this diagnosis, travel or time apart?
 - Has it been difficult to manage the day to day responsibilities at home for example paying the bills, housekeeping, grocery shopping. Do you think that this would be different if you lived closer to your cancer specialists?
- 5) What suggestions do you have for health care providers and other professionals about how we can support people living with cancer from rural areas?
- 6) Is there anything else you would like to talk about that you feel is important for me to know?
- 7) Are there any additional questions which you think I should be asking in this interview?
- 8) Are there any issues which we have not covered which you think we should?

Appendix M

Second Interview Guide

- 1) How have you been doing since we last met?
- 2) Is there anything you would like to talk about based on your overall experience?
- 3) What does life after cancer mean to you?
- 4) What are the best ways to handle a major illness such as breast cancer?
- 5) What made you feel most supported throughout your illness?
- 6) What made you feel not supported throughout your illness?
- 7) Considering any knowledge you had about cancer prior to your diagnosis, how has that impacted your experience?
- 8) Can you discuss the impact of having to leave your community for your cancer treatments?
- 9) Can provide a description that compares the care you received in rural areas to the care you received from CCMB in the urban setting?
- 10) Do you feel your care was delivered in a timely manner? Can you elaborate?
- 11) Can you tell me how you feel about your cancer follow now you have completed all the therapies? Do you feel comfortable with this plan?
- 12) How do you feel about being followed post treatment by your family doctor and not your oncology team in Winnipeg?
- 13) When you were discharged from care from Winnipeg were you given the information you needed to feel comfortable with your follow up?
- 14) Considering the complexity of a cancer experience and treatment, is there anything that would have made your journey easier?
- 15) Can you tell me about the role of navigation as it relates to your experience? The role of telehealth?
- 16) What are things that may affect the quality of care a person may get from your HCP?
- 17) What did your HCP tell you to do to get well?

18) What is the most important resource or coping strategy that you utilized during your cancer experience? Can you elaborate on why? Was it available in rural MB?

19) Can you describe what it means to be a cancer survivor?

20) Is there anything else that you would like to talk about?

Appendix N

Ethics and Approvals



Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Fax +204-269-7173

APPROVAL CERTIFICATE

March 25, 2015

TO: Joanne Loughery (Advisor R. Woodgate)
Principal Investigator

FROM: Lorna Guse, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2015:015
"Supportive care experiences of rural women living with breast cancer:
An interpretative descriptive qualitative study"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, please mail/e-mail/fax (261-0325) a copy of this Approval (identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) **in order to be in compliance with Tri-Council Guidelines.**



**UNIVERSITY
OF MANITOBA** | Research Ethics
and Compliance

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Email: humanethics@umanitoba.ca

RENEWAL APPROVAL

Date: February 27, 2018 **New Expiry:** March 23, 2019

TO: Joanne Loughery
Principal Investigator **(Advisor: Roberta Woodgate)**

FROM: Zana Lutfiyya, Chair
Education/Nursing Research Ethics Board (ENREB) [REDACTED]

Re: Protocol #E2015:015 (HS17484)
"Supportive Care Experiences of Rural Women living with Breast Cancer:
An Interpretative Descriptive Qualitative Study"

Education/Nursing Research Ethics Board (ENREB) has reviewed and renewed the above research. ENREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

This approval is subject to the following conditions:

1. Any modification to the research must be submitted to ENREB for approval before implementation.
2. Any deviations to the research or adverse events must be submitted to ENREB as soon as possible.
3. This renewal is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
4. A Study Closure form must be submitted to ENREB when the research is complete or terminated.

Funded Protocols:

- Please mail/e-mail a copy of this Renewal Approval, identifying the related UM Project Number, to the Research Grants Officer in ORS.



BRANDON

**Brandon Regional Health Centre
Research Office
Dr. Charles Penner
N403 Nurse's Residence
150 McTavish Avenue East
Brandon, MB R7A 2B3
Phone: 204-578-4343 | Fax: 204-578-4969**

July 15, 2015

Ms. Joanne Loughery
[REDACTED]

Dear Ms Loughery:

I am pleased to provide you with approval for conducting the study, *Supportive Care Experiences of Rural Women Living with Breast Cancer: An Interpretative Descriptive Qualitative Study* in the PMH region. Scott Kirk will be your contact person for helping to advertise the study and to connect you with other health centers in the region. He can be contacted by phone at [REDACTED]. His e-mail address [REDACTED].

Enclosed find PMH Ethics Committee approval as well.

Please forward a copy of your completed research to me when the project is done.

Sincerely,

[REDACTED]

Charles Penner MD FRCPC
Research Facilitator
Prairie Mountain Health
[REDACTED]

cc: Scott Kirk, Director – Operations Manager, Western Manitoba Cancer Program
Pat Cockburn – Senior Advisor, Acute Care & Nursing
Shaun Gauthier – Chief Medical Officer, Prairie Mountain Health



867 Thompson Drive South
Thompson, MB, R8N 1Z4
Telephone: (204) 677-5376
Fax: (204) 680-3050

October 2, 2015

Joanne Lougher, RN, BN, MB (Student)
Graduate Nursing Student
Primary Research, Faculty of Health Sciences
College of Nursing, University of Manitoba

Dear Ms. Loughery,

Thank you for addressing the concerns that the Northern Health Region Ethics Committee had regarding your research project "Supportive Care Experiences of Rural Women Living with Breast Cancer: An Interpretive Descriptive Qualitative Study".

I am pleased to inform you that Northern Regional Health Authority (NRHA) approval has been granted for this research project as per NRHA's Policy.

Please find attached copies of the completed Appendixes A and B and the Regional Ethics Committee's approval letter.

I look forward to seeing the results from this endeavor.

Sincerely yours,



Dr. Hussam M. Azzam, MD, MMedEd, FRCSC, MRCOG, FACOG, CCPE
Vice President for Medical Services, Chief Medical Officer
Senior Executive for Research
Northern Health Region, Thompson General Hospital

Cc: Helga Bryant

Northern Regional Health Authority Regional Offices

84 Church Street
Flin Flou MB R8A 1L8
(204) 687-1300 (888) 340-6742

67 - 1st Street West
The Pas MB R9A 1K4
(204) 623-6431 (888) 340-6742

867 Thompson Drive South
Thompson MB R8N 1Z4
(204) 677-5350 (888) 340-6742



Southern Health-Santé Sud
 Quality, Patient Safety & Risk
 180 Centenaire Drive/180 rue Centenaire
 Southport MB R0H 1N1
 T 204-428-2720 or/ou 1 800 742 6509 | F 204-428-2779
 www.southernhealth.ca

June 1, 2015

Joanne Loughery RN BN MN
 Faculty of College of Health Sciences, College of Nursing
 University of Manitoba
 Winnipeg MB R3T 2N2
 [REDACTED]

Dear Joanne,

Thank you for your request to conduct research in Southern Health-Santé Sud. Your research proposal titled **Supportive care experiences of rural women living with breast cancer: An interpretive descriptive qualitative study** has been reviewed by Southern Health-Santé Sud.

After careful consideration it has been determined that your proposal meets the requirements to conduct research in Southern Health-Santé Sud until your Research Ethics Board (REB) approval expires March 25, 2016. Should you wish to continue your research please submit your renewed REB approval prior to expiry to [REDACTED]

Your Southern Health-Santé Sud contact is:

NAME: Heidi Wiebe POSITION: Regional Director Seniors/Palliative Care

PHONE: [REDACTED] EMAIL: [REDACTED]

The region is interested in reviewing the results of your research study and would appreciate a copy of the results sent to Kristine Hannah, Regional Director Quality, Patient Safety & Risk at [REDACTED]

*Ensemble vers un avenir plus sain.
 Together leading the way for a healthier tomorrow.*

On behalf of Southern Health-Santé Sud, thank you for your interest in conducting research in the region. We wish you all the best in your study.

Kindest regards,

[Redacted Signature]

Kristine Hannah
Regional Director Quality, Patient Safety & Risk

- cc. Heidi Wiebe, Regional Director Seniors/Palliative Care
- Paulette Goossen, Executive Director-West
- Angie Cusson, Director of Health Services-Boundary Trails Health Centre
- Jan Gunness, Director of Health Services-Bethesda Regional Health Centre
- Noreen Shirliff, Director of Health Services-Portage District General Hospital



4. What contact will you require with staff? With clients?

Recruitment will commence once all ethics approvals are in place. A number of intermediaries will be approached to identify potential participants for the study. The following rural staff will be asked to identify and approach potential women to participate in the study. The intermediaries will be orientated to the study via presentations and email correspondence. They will be provided with the resources they need for recruitment including, Study Information for Recruitment Sites and Recruitment letter. This documentation is included in this package of information.


The intermediaries that will be used in the study include:

- 1) Rural Patient Navigators
- 2) Community Cancer Program Nursing and Medical Staff
- 3) Nurse Navigator at Breast Cancer Center of Hope

5. What requirements will you have in the region/facility/site (ie. Supplies, equipment, space)?

It is anticipated that the women will be interviewed in a setting of their choice such as their home or other pre-arranged location. If space is required in an IERHA setting it will be arranged on a case by case basis through the rural CCP contacts.



Signature of Applicant


Signature of Faculty Advisor
(Students Only)

Approval Granted: 

Request Denied: _____

Date June 15 / 2015


Signature of Responsible Vice President



CancerCare
MANITOBA
Action Cancer Manitoba

May 7, 2015

Joanne Loughery
University of Manitoba, College of Nursing



© 675 McDermot Avenue
Winnipeg MB R3E 0V9
Canada

© 409 Taché Avenue
Winnipeg MB R2H 2A6
Canada

www.cancercare.mb.ca

Re: RRIC #2015-003: Supportive care experiences of rural women living with breast cancer: An interpretative descriptive qualitative study

The above-named study has been approved by the CancerCare Manitoba (CCMB) Research Resource Impact Committee (RRIC).

The following departments at CCMB have signed off on this study: Patient and Family Support Services.

According to the CCMB RRIC submission form that you completed, NO CCMB paper charts will be required for this study and the study expected duration is 1 year.

A copy of the signed CCMB PHIA form for research is appended to this letter.

ANY SIGNIFICANT CHANGES TO THIS RESEARCH PROJECT MUST BE REPORTED TO THE RRIC BY SUBMITTING A "REQUEST FOR AMENDMENT FORM" FOR CONSIDERATION IN ADVANCE OF IMPLEMENTATION OF SUCH CHANGES. Significant changes include (but are not limited to): a change in the study design or in the data to be collected; a change in the study duration, the patient cohort to be studied, or the number of participants to be studied; the need to review CCMB paper charts (when not originally planned) or the need to review significantly more CCMB paper charts than originally planned; the addition of other trainees or co-investigators to the project; or the inclusion of additional individuals who will have access to the data or database.

Please cite the RRIC number for this study in all future correspondence with the RRIC about it. Please note that annual approval is not required if there are no changes to the project (as outlined above).

This approval is for RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required.

Yours sincerely,



Rochelle Yanofsky, MD FRCPC
Chair, CCMB Research Resource Impact Committee

Enclosure: Signed CCMB PHIA Form for Research

cc: Jill Taylor-Brown – Patient and Family Support Services
Jacqueline Sholdice - Privacy Officer
Maureen Crump – Paper Charts
File copy


CancerCare Manitoba
 RESEARCH RESOURCE IMPACT COMMITTEE
Disease Site Group
Study Approval Form

Study Title:	Supportive Care Experiences of Rural Women Living with Breast Cancer: An Interpretative Descriptive Qualitative Study
Principal Investigator:	Joanne Loughery RN BN Graduate Nursing Student University of Manitoba
Study Sponsor (if applicable):	



Disease Site Group:	Breast Disease Site Group
Disease Site Group Chair:	Dr. Saroj Niraula
Address:	675 McDermot Avenue
Phone:	204-787-1992
Fax:	
E-Mail:	sniraula@cancercare.mb.ca

Do any trials currently open at CCMB conflict with this trial or compete for the same patient population?

No Yes

If yes, please justify:

Approval by DSG Chair or Designate: (If DSG Chair is involved in study, an alternative member of the DSG must sign)

	
Print Name	Signature
	
	Date

Note: If more than one DSG is affected by this study, a form must be signed and submitted for all applicable DSGs.

Appendix O

Consent Form

Project Title

Supportive Care Experiences of Rural Women Living with Breast Cancer: An Interpretative Descriptive Qualitative Study

Principal Investigator

Joanne Loughery RN BN
Graduate Student
Faculty of College of Health Sciences, College of Nursing
University of Manitoba

Thesis Advisor

Dr Roberta L. Woodgate RN PhD
Canadian Institutes of Health Research Applied Chair in Reproductive, Child and Youth Health Services and Policy Research
Professor, Child Health and Illness
Faculty of Health Sciences, College of Nursing
University of Manitoba

Co-Investigators

Internal Member:
Dr. Susan McClement RN PhD
Professor
College of Nursing, Faculty of Health Sciences
University of Manitoba

External Committee Member:
Megan McLeod MSW
Supportive Care Coordinator:
Community Cancer Program
CancerCare, MB

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, agree to participate in the above study. I have been told that the purpose of the study is to explore experiences and supportive care needs of women living with breast cancer who live in rural areas of our province. I understand that what is learned from this study will be shared with professionals who work directly with cancer patients. I understand that from this study, recommendations on how to improve the supportive care experiences of rural women living with breast cancer in the province may be provided.

I understand that if I agree to participate in this study, I will be asked to participate in two audio-taped recorded interviews, at a setting of my choice, that are expected to take one to two hours

long. I understand that Joanne Loughery, Master of Nursing student, under the supervision of Dr. Woodgate, will be doing the interviews. I will be asked questions about my experience of living with breast cancer from the time of my diagnosis to the end of my treatment. I also understand that a second interview is requested but I may decline this interview if I do not wish to be interviewed again. I also understand I will need to fill in a short form that will take approximately 15 minutes to complete. I understand that the short form includes demographic and health information. I am also aware that all the materials from this interview will be kept confidential and my identity or place of residence will not be revealed at any time. Only the principal investigator and her advisor will have access to these materials and they will be securely stored at all times.

I understand that my participation in this research is completely voluntary. I understand that my physicians and nurses who care for me will not know I decided to participate in this study. I understand that I may withdraw at any time and refrain from answering any questions without consequence. I understand that if I wish to withdraw from the study, I may contact Joanne Loughery by phone or email and that upon withdrawal all data collected about me will be destroyed.

I understand that there are no direct benefits for me to participate in this study. However, I am aware that the study may help health care professionals understand the needs and services that are required for rural women living with breast cancer.

I understand that there are some risks to me in participating in this study. I am aware that talking about my experiences might stir up emotions and feelings. If I become upset and need to stop the interview I may do so at any time. If I need to talk to someone further about my feelings, I understand that additional resources are available to me (see “additional information” below).

I understand that the results from this study may be presented at professional conferences or published in a professional journal. I am aware, that in all instances, that my name, place of residence or anything that can reveal my identity will be protected. Only Joanne Loughery, the principal investigator will have access to my name. I understand that my name will be replaced with a code number so no-one will be able to identify me. I have also been informed that all the audio recording will be transcribed by a qualified transcriptionist who is bound by Personal Health Information Act and has signed a pledged confidentiality agreement. I understand that Dr Woodgate, Joanne Loughery and the transcriptionist will be the only persons who have access to the taped interview and the written interview may be shared with the other members of the committee.

I understand that confidentiality will be maintained at all times except in situations in which there are legal requirements to disclose identity such as abuse. I understand the all materials from this study which include, consent forms, demographic information, researcher notes, tape materials and interview transcripts will be securely locked in a file cabinet and computer generated material will be password protected only known to Joanne Loughery. I am aware that all of my information will be destroyed five years (December, 2020) after the study is completed, paper files will be shredded, computer files deleted and digitally taped data will be erased. I am aware that if I decide to participate, that a summary of the study will be provided to me if requested.

My signature on the form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive my legal rights nor release the researchers, or involved institutions from their legal and

professional responsibilities. I understand I may withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. I understand that my continued participation should be as informed as this initial consent, and I should feel free to ask for clarification or new information throughout my participation. I understand I may contact Joanne Loughery or Dr. Roberta Woodgate if I have concerns, questions or need additional information.

I understand that this research has been approved by the Education/Nursing Research Ethics board at University of Manitoba, the Research Resources Impact Committee at CancerCare MB and in the Regional Health Authority where I reside. If I have any concerns or complaints about this project, I may contact any of the above-named persons or the Human Ethics Coordinator. A copy of this consent form has been given to me to keep for my records and reference.

Additional Information:

1) Participation in this study may be upsetting or distressing to you as you recall your own cancer experience, or the experience of your family member. If you would like to talk to someone about this, there is support available through your Regional Cancer Program. Please call Elizabeth Payne, Supportive Care Coordinator, Community Oncology Program, or ask the research study staff to refer you.

2) The University of Manitoba may look at my records to see that research is being done in a safe and proper way. If you have any concerns contact Human Ethics Coordinator.

I agree to take part in the first interview. Yes _____ No _____

I agree to take part in the second interview. Yes _____ No _____

Participant's Signature _____

Date _____

Researcher's Signature _____

Date _____

I would like a copy of the report findings. Yes _____ No _____

Mailing address: _____

Thank-you for agreeing to participate in this masters research study which will help us seek the knowledge we need to improve service for rural women living with breast cancer in our province. We appreciate your valuable time, effort and insight to this important health topic.