Decision Making Across the Adult Lifespan in the Context of Breast Cancer

by

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Abstract

Background: Approximately 1.4 million women are diagnosed with breast cancer worldwide annually. Most newly diagnosed women face multiple treatment decisions, and want information about their disease and its treatment when making these decisions. While prior research investigates the psychosocial impacts of breast cancer, little is known about those impacts on the experience of decision making or how age influences decision making. There is a need to conduct research exploring this experience.

Purpose: To develop an understanding of the experience of decision making for women diagnosed with breast cancer across the lifespan. Specific objectives were to explore: 1) the meanings women assigned to decisions; 2) how psychosocial factors influenced the decision making experience, and; 3) similarities and differences in decision making across the lifespan.

Method: The tenants of constructivist grounded theory were followed. Twenty-nine semi-structured interviews were conducted with 22 women with invasive breast cancer. Women ranged in age from 32 to 80 years of age (average=55 years). Participant data was grouped by age: younger women, under 45 years (N=7), middle aged women, aged 45-64 years (N=9), and older women, aged 65 and older (N=6). Data was analyzed using the constant comparison method of data analysis.

Findings: Women with breast cancer described the experience of treatment decision making soon after diagnosis, and described their needs regarding information about cancer and its treatment. Main findings include a model depicting the process of the *ways of learning in breast cancer*. Two ways of learning were described by women, “learning by trusting the healthcare system” and “learning by trusting a system of connections.”

Women reported barriers to information support, including emotional distress, patient-provider communication, provider-provider communication, making it personal, and access to information. Similarities and differences between age groups are presented.

Conclusion: Diagnosed women want information about cancer and its treatment regardless of their ages. Ways of learning in the context of breast cancer guide women as they worked to make treatment decisions, yet barriers to information support exist in breast cancer, occurring at the patient, provider, and health system levels.

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Dedication

For my parents, David and Rosemarie Campbell. You have inspired me to be a lifelong learner, and you have encouraged your children and grandchildren to carve our own paths and to be of use in the world. Thank you.

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Structure and Organization of the Thesis

This thesis is a paper-based, or manuscript style, thesis. As such, the findings are composed of three chapters, an introduction to the findings and two chapters written in manuscript style. Otherwise, the thesis is organized much like a standard thesis, including sections for an introduction, review of the literature, study design, findings, discussion, and conclusion.

The chapters are as follows: chapter one is an introduction to the thesis topic; chapter two is an overall review of the literature pertaining to the epidemiology of breast cancer, the psychosocial aspects of breast cancer, and decision making research; chapter three provides a description of the study design, including the epistemological and theoretical perspectives used, the methodology and methods; chapter four-six describe the findings of the study, with chapter four providing an introduction to the findings, and chapters five and six being separate manuscripts which describe main aspects of the findings; and chapter seven provides an overall discussion of the findings and a conclusion to the thesis.

Concerning the manuscript chapters (chapters five and six), each manuscript includes background, method, findings and conclusion sections. As a result, redundancies are present between papers, as each has been written to be a separate publishable paper. Also, while the citation references for chapters one-four and chapter seven are located at the end of the thesis document, the references referred to within the texts of the manuscript chapters are found at the end of each chapter.

Finally, the literature review for this thesis occurred in two phases. First, a review of the literature was undertaken prior to data collection, to inform the study design (see chapter two). Then, after categories of analysis came forward, it was noted that this initial literature review needed expanding. As a result, a second phase was undertaken where background literature was tailored for the specific focus of each manuscript (see chapters five and six). These reviews ensure that the study findings presented in each manuscript are firmly placed into the context of the pertinent, and current, literature.

In relation to the literature review, this activity provided incentive to complete a systematic review looking at the psychosocial experiences of women with breast cancer across the lifespan. Although not a requirement for this thesis, the protocol for this review has been published (Campbell-Enns & Woodgate, 2015). This is a meta-ethnographic review of qualitative research in this area.

CHAPTER 1: INTRODUCTION

Breast cancer is the most diagnosed cancer in women throughout the world with approximately 1.4 million women diagnosed each year (Ferlay, Shin, Forman, Mathers, & Parkin, 2010). It was estimated that nearly 23,000 Canadian women were diagnosed with breast cancer in 2012, including approximately 800 women in Manitoba (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012). While mortality rates slowly decline worldwide (Althuis, Dozier, Anderson, Devesa, & Brinton, 2005), the incidence of breast cancer continues to rise (Althuis et al., 2005) which indicates the significance of breast cancer in the population. Worldwide data (Ferlay et al., 2010) reveals that approximately half of all breast cancer diagnoses are among women aged 55 years and older, a little more than one quarter of diagnoses are in women aged 45 to 54 years, and just under one quarter are diagnoses in women under age 45 years. This shows that the burden of disease rests mainly with older women, however a great number of younger and middle-aged women contend with the disease as well.

The diagnosis of invasive breast cancer brings with it adversity due to physical concerns as well as psychosocial challenges for women of all ages. Psychosocial distress may be present for women with breast cancer as they experience a time of fear (Stanton, Danoff-Burg, & Huggins, 2002) and uncertainty (J. P. Nelson, 1996) which challenges their identity (Lally, 2009), body image (Helms, O'Hea, & Corso, 2008) and close relationships (Faulkner & Davey, 2002; Fergus & Gray, 2009; Raveis, Pretter, & Carrero, 2010). Research comparing the psychosocial needs of younger and older women with breast cancer is limited, yet existing literature points to the cancer experience being different across the lifespan (Mor, Allen, & Malin, 1994; Stava, Lopez, & Vassilopoulou-Sellin, 2006).

Decision making is crucial in cancer care (W. Nelson, Stefanek, Peters, & McCaul, 2005). While society dictates that patients are expected to make decisions which conform to clinical standards, little research seeks to explore how patients *actually* respond in real-world health decision making contexts (Fischhoff, 2005). From a person-centered perspective, it could be explained that a “good” decision is one made based on the values, needs and preferences of the patient (Davies, Rhodes, Grossman, Rosenberg, & Stevens, 2010). Unfortunately, little research about patient decision making can be found in breast cancer literature. Furthermore, patient interventions (such as decision making tools) are created on the assumptions of clinical expectations of what is a good decision (W. Nelson et al., 2005) rather than theory derived from patient decision making research. It is unknown if there is a gap between decision making that is clinically optimal (Stanton et al., 1998) and the actual, real-word experience of decision making for women diagnosed with invasive breast cancer.

As a student in Interdisciplinary Cancer Control, I am interested in how humans experience highly complicated health situations. I have a particular interest in patient decision making and how the experience may be influenced by factors such as life stage, gender, and psychosocial conditions. This study has been built upon the foundation of my Master of Science thesis, which has acted as a pilot study for the design of this present research. The study explored decision making among young mothers with cancer (Campbell-Enns & Woodgate, 2013). Most of these mothers had a diagnosis of breast cancer but other cancer diagnoses were present as well. The findings revealed that health decisions were interconnected and the mothering identity influenced decision making in cancer. Mothers were influenced by their values and needs related to their relationship bonds with their children and decisions in the context of cancer were motivated by these influences. It remains unknown if women who are not mothering are affected by relationship bonds in decision making or how decision making changes across the lifespan. Further, gender (Canadian Institutes of Health Research, 2012) showed to be influential in motivating these women's health decisions. A small number of studies show that gender influences the cancer journey (Boehmer, Linde, & Freund, 2007; Granek & Fergus, 2012; Greif, Pezzi, Klimberg, Bailey, & Zuraek, 2012; Rager, 2007; Rubin & Tanenbaum, 2011; Shaaban et al., 2011). As a result, both gender and lifespan are key perspectives from which to study health decision making in the context of cancer. Where developmental change across the lifespan is a main issue to be explored in this study, a gender perspective lens will be used to view these changes.

Purpose

Although much has been learned about the psychosocial impacts of invasive breast cancer, little is known about those impacts on the experience of decision making or how a woman's age affects her decision making. When physical and psychosocial outcomes partially rest on decisions made, there is a need to conduct research aimed at understanding how women experience decision making across the lifespan in the context of invasive breast cancer. Thus, the overall purpose of this study was to explore the decision making experience in the early cancer journey for women with invasive breast cancer across the adult lifespan. "Decision making" focused on treatment decisions early after cancer diagnosis, but decisions were not limited to these; women had the opportunity to discuss any decision that was important to them since diagnosis. The aim was to develop a theoretical understanding of the experience of decision making for women diagnosed with breast cancer across the lifespan.

The specific research questions included:

1. What meanings do women assign to decisions?
    a. Meanings refer to the process of meaning making, whereby women make sense of decisions to be made within the context of breast cancer; possibly integrating the illness into their lives (Schulman-Green, Wagner, & McCorkle, 2015)
2. How do psychosocial factors influence the decision making experience?
    a. Psychosocial factors include the psychological, emotional, spiritual, quality-of-life and functional aspects of cancer (Canadian Association of Psychosocial Oncology, 2015).
3. How does decision making change across the adult lifespan?
    a. Lifespan changes refer to continuous, developmental changes that occur throughout life, including both growth and decline (Fasokun, Katahoire, & Oduaran, 2005; Hendry & Kloep, 2002).

Assumptions

1. Cancer affects the whole person (Nancy E. Adler & Page, 2008).
2. Persons with cancer have a variety of psychosocial needs which impact their experience; many psychosocial needs are under-studied and unmet (Sanson-Fisher et al., 2000).
3. Decision making is crucial to cancer care (W. Nelson et al., 2005).

4. Human development is holistic and marked by change; internal and external forces are resources for development (Lerner & Overton, 2010).
5. Women of different ages have different needs in cancer (Siegel, Gluhoski, & Gorey, 1999).
6. Gender is a social concept (Canadian Institutes of Health Research, 2012); gendered understandings of body image, connectedness with others, and personal/cultural values influence the experience of cancer (Boehmer et al., 2007; Granek & Fergus, 2012; Rager, 2007; Rubin & Tanenbaum, 2011).
7. Research participants are experts on their experiences and needs (Letherby, 2003).
8. Research itself is not therapeutic and yet the act of telling one's story promotes healing (Frank, 1997).
9. Although a participant may make decisions that are unexpected or surprising to others, they are worthy of the researcher's respect. Listening to participant stories with compassion is an effort to convey respect, as well as aid in creating a sense of dignity and self-worth for the participant and others involved in the life and care of that patient.

Significance

Through examining the literature, it is apparent that decision making in the context of cancer does not correspond with traditional decision making theory and yet there is a paucity of research regarding patient decision making in cancer. Where many breast cancer studies do not compare younger and older women with breast cancer, the limited existing research shows that the experience of cancer changes dependent partly on the diagnosed woman's age. This study contributes to the existing body of literature by presenting an understanding of the experience of decision making for women of various ages with invasive breast cancer diagnoses. Further, this study provides a model that, in the future, may be extended to theory development in the area of health decision making. The model describes decision making across the lifespan from a patient perspective, providing grounding for future decision making research in cancer and informing best practices for supporting women of all ages in treatment decision making in the context of breast cancer. Understanding the needs of women of various ages making decisions in the context of cancer enables patients, family members, and practitioners to better support each other after a cancer diagnosis.

Summary

Breast cancer occurs in women across the adult lifespan and brings with it a range of psychosocial concerns. Decision making in cancer is complex and patients make decisions that can be unexpected. This study explored the decision making experience in women with breast cancer from gender and lifespan perspectives.

CHAPTER 2: LITERTURE REVIEW

Literature is reviewed in an effort to provide a backdrop of existing knowledge in which to situate the purpose of this study. This review of the literature is presented to explore the following areas: 1) the descriptive epidemiology of breast cancer; 2) the psychosocial impact of breast cancer, including the challenges to identity, body image and relationships; 3) decision making in cancer, including decision making in breast cancer, and; 4) the psychosocial impact of breast cancer on decision making. Existing lifespan research will be reviewed in each section and gender research is included when possible.

Descriptive Epidemiology of Breast Cancer

Incidence and Mortality

Breast cancer is the most frequently diagnosed type of cancer among women with an estimated 1.38 million new cases diagnosed worldwide in 2008, at an age standardized incidence rate of 38.9 per 100,000 persons (Ferlay et al., 2010). This accounts for 22.9% of all adult female cancers (Ferlay et al., 2010) and 10.9% of all adult female and male cancers combined. In Canada, it is estimated that 25.9% of new female cancer diagnoses in 2015 will be diagnoses of breast cancer (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015) More local to this study, 848 women in the province of Manitoba received a diagnosis of invasive breast cancer in 2012 (CancerCare Manitoba, 2012). This accounts for 27.7% of all invasive cancer diagnoses among women, and 14.2% of the total incidence of invasive cancer for adult Manitobans (CancerCare Manitoba, 2012).

More than 450,000 deaths were attributed to breast cancer worldwide in 2008 (Ferlay et al., 2010), with an age standardized mortality rate of 12.4 per 100,000 persons (Ferlay et al., 2010). This accounts for 13.7% of all adult female cancer deaths and 6.1% of all worldwide cancer deaths for adult females and males combined (Ferlay et al., 2010). In Canada, cancer remains the top cause of mortality (CancerCare Manitoba, 2009) and has become the leading cause of mortality in every province and territory (CancerCare Manitoba, 2009). The Canadian Cancer Society (2012) reports an estimated 5,100 deaths due to female breast cancer in 2012 with an estimated age-adjusted mortality rate of 19 per 100,000 persons (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012) accounting for 14.0% of total adult female cancer deaths and 6.7% of total cancer deaths among adult Canadians (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012). The Manitoba Cancer Registry reported a female breast cancer age-standardized mortality rate of 26.01 per 100,000 persons in 2011 (CancerCare Manitoba, 2011). The number of female deaths in Manitoba due to breast cancer was 192 in 2011, explaining 15.04% of all adult female invasive cancer deaths and 7.2% of all adult cancer deaths in Manitoba that year (CancerCare Manitoba, 2011).

Types of Breast Cancer

Breast cancer comes in several forms, and the correct diagnosis is crucial so that the diagnosed woman has the opportunity to make decisions that are best able to lead her to the outcome she desires. Many women with a breast cancer diagnosis have a diagnosis of in situ cancer, meaning that the abnormal cells have been determined to be non-invasive or pre-cancerous. In situ cancer are usually found in the milk ducts (DCIS) or breast lobules (LCIS) (BC Cancer Agency, 2012). The most common invasive breast cancer is Invasive Ductal Carcinoma (IDC) which begins in the breast ducts and grows into the normal tissue of the breast (BC Cancer Agency, 2012). Less common subtypes of IDC may include the tubular, medullary, mucinous, papillary, and medullary carcinomas of the breast (National Cancer Institute, 2012). More rare still are other forms of female breast cancer, including the non-invasive diagnosis of Paget's Disease and invasive diagnoses such as Invasive Lobular Carcinoma (ILC), Inflammatory Breast Cancer (IBC), Phyllodes Tumours (connective tissue), locally advanced, recurrent or metastatic breast cancer (BC Cancer Agency, 2012). From a gender perspective, research has shown that breast cancer may be histologically different in males and females (Greif et al., 2012; Shaaban et al., 2011), particularly in terms of the hormone receptor profiles of individuals with breast cancer (Shaaban et al., 2011). However, Greif et al (2012) contends that male and female breast cancer are more alike than not, and more research must be conducted from a gender perspective.

Cancer may spread through the body via tissues, the lymph system or through the blood, by breaking away from the original tumour and traveling to another site in the body (National Cancer Institute, 2012). Staging a cancer, or the process of determining the spread of the disease though examination of the tumour and lymph nodes, is crucial in developing a plan of treatment which involves examining tumor site, size, and grade, as well as evidence of lymphovascular invasion (National Cancer Institute, 2012) and hormone sensitivity. Breast cancer includes Stage 0 (DCIS, LCIS, Paget's Disease), Stage I A, B; Stage II A, B; Stage III A, B, C, and; Stage IV (National Cancer Institute, 2012). CancerCare Manitoba (2012) reported that the majority of women diagnosed with invasive breast cancer in 2012 were diagnosed with Stage I (42.7%) or Stage II (34.7%)

cancer. Considerably fewer women were diagnosed with Stage III (14.6%) or Stage IV (6.7%) cancer, while the staging of 1.5% of women was unknown.

Geographical Variation

From a global perspective, there is a large range in the incidence rate of breast cancer by geographic region, with higher incidence rates in developed regions (80 per 100,000 persons), and lower rates in developing regions (40 per 100,000) (Ferlay et al., 2010). The mortality rates have a smaller range worldwide, likely due to more favorable breast cancer survival rates in developed countries (Ferlay et al., 2010).

The Canadian Cancer Society (2012) reports no evidence of differences found from province to province when studying breast cancer incidence and mortality rates. However, in Manitoba, it has been shown that the overall cancer incidence and mortality rates among Manitoban women appears to change when examining the north-south gradient, with the northern areas reporting more cases of invasive cancer among women and poorer mortality rates overall (CancerCare Manitoba, 2009). It is unknown if this holds true across Canada at this time.

Variation by Age

The impact of age on the incidence and mortality of breast cancer may be analyzed in a general way, by grouping breast cancer data into younger and older groups. When grouping women age 49 and younger, and comparing this group to women to aged 50 and older, it shows that the majority of female invasive breast cancer diagnoses occur in the older age group worldwide (66.83%) (Ferlay et al., 2010), in Canada (85.6%)

(Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015), and in Manitoba (83.2%) (CancerCare Manitoba, 2012).

To delineate age groups further, it may be beneficial to utilize the generalization of premenopause (<45 years), perimenopause (45 to 54 years), and postmenopause (>55 years) (Stava et al., 2006), because there is a marked increase in diagnoses among women at midlife (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012). Unfortunately this data is unavailable for Canada and Manitoba, but when the worldwide data is grouped in this way the premenopausal and perimenopausal groups experience similar proportions with 20.7% and 25.9% (Ferlay et al., 2010) respectively, while approximately half of all diagnoses (53.4%) occur in the postmenopausal group worldwide (Ferlay et al., 2010). This confirms that the breast cancer occurs most often in the oldest group of women, but it also reveals that the youngest group shoulders the burden of diagnoses nearly as often as the middle aged group.

Similarly, mortality data for ages 49 and younger, compared with ages 50 years and over, shows that mortality due to breast cancer impacts older women most worldwide (75.9%) (Ferlay et al., 2010), in Canada (81.1%) (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012), and in Manitoba (87.5%) (CancerCare Manitoba, 2010). When grouping worldwide mortality data into three age groups, results show that the premenopausal group has the lowest mortality (14.7% of breast cancer deaths) (Ferlay et al., 2010), the perimenopausal group shows a slight increase (22.0%), and the postmenopausal group experiences the highest mortality (63.6%).

Time Trends

Utilizing three decades of data from 1973 to 1993, Althuis el al. (2005) showed a trend of increasing incidence in breast cancer worldwide. This trend does not appear to show patterns due to geography or ethnicity (Althuis et al., 2005). Regions with large increases, showed this to be the case in all age groups (30-49 years; 50-64 years; 65-79 years); but a marked increase in diagnoses among women aged 50 years and older was prominent worldwide (Althuis et al., 2005). Two main patterns of incidence were found, typified by the experiences of Japanese women and Caucasian women in the United States (Althuis et al., 2005). The US Caucasian pattern shows that incidence rates rise with age, while the Japanese pattern shows that incidence plateaus after age 50 years. These results point to the possibility of hereditary risks for the development of breast cancer, with the addition of social and environmental risks, including an exposure to estrogen (Althuis et al., 2005). This is also shown in the possible age cohort effect for Asian women, where these women are a part of a culture that experiences a growing acceptance of western practices concerning fertility, diet and lifestyle (Althuis et al., 2005). As a result, the trends may change as women across the globe adopt different social and environmental practices.

Unlike incidence rates, mortality rates have declined worldwide (Althuis et al., 2005). A trend to note is the decline in mortality in Canadian, US Caucasian, and Swedish women (Althuis et al., 2005; Cancer Projections Network (C-Proj), 2010; Katanoda & Yako-Suketomo, 2010) while there has been a rise in mortality among Japanese, Colombian, Polish, and US African American women (Althuis et al., 2005; Katanoda & Yako-Suketomo, 2010). Geographic patterns cannot be found to explain mortality trends

(Althuis et al., 2005) but early detection, screening programs, and improved treatment may be responsible for some decreasing trends while areas with increasing mortality rates may have less access to care (Althuis et al., 2005), in combination with increased risks.

In Canada, time trends reveal that the incidence of breast cancer has experienced modest fluctuations in the past few years (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012), while mortality rates have slowly declined (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2012). In Manitoba, incidence rates continued to climb through the mid-1990s (Cancer Projections Network (C-Proj), 2010), possibly due to a growing and aging population (Demers, Turner, Mo, & Kliewer, 2005). Within the last few years the incidence rate of invasive breast cancer in Manitoba has leveled (Cancer Projections Network (C-Proj), 2010). Similar to the Canadian trend, mortality rates associated with invasive breast cancer deaths have slowly declined in Manitoba (Cancer Projections Network (C-Proj), 2010; Demers et al., 2005).

Outcomes

Information regarding incidence and mortality provide the basis of determining the implication of disease on the population, by estimating the burden of disease through survival and prevalence data. Outcome data is difficult to ascertain throughout most jurisdictions (Demers et al., 2005) and comparing existing prevalence data is challenging when various methods of estimation may be used (Demers et al., 2005). It is known that, in 2009, 2.4% of all adult Canadians had been diagnosed with cancer in the past ten years (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). Also, breast cancer accounts for 18.8% of 10-year prevalence cancers for all adults, reflecting both the frequency and prognosis of the disease (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015).

Demers et al. (2005) report Manitoba to have had the highest incident rate of breast cancer in Canada between 1990 and 2000 (105.8 per 100,000 women), but the age-standardized mortality rate was average when compared to the overall Canadian rate (28.9 per 100,000 women). This is consistent with current statistics that show an estimated 26.1% of cancers being attributed to female breast cancer, compared to 25.9% of cases across the country (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015). While incidence rates in Manitoba show signs of stability, these incidence rates paired with declining mortality rates suggest increasing prevalence of the disease in Manitoba. While this is welcome news for women with breast cancer and their families, it does point to the fact that the burden of disease due to breast cancer is increasing, and therefore breast cancer is a significant concern for Manitobans (Demers et al., 2005).

Survival data, another descriptor of breast cancer outcomes, indicates burden due to the early portion of the cancer journey. This includes the time of 1) diagnoses and treatment, 2) clinical follow-up, and; 3) ongoing care during survivorship. These time intervals are often reported as one-year survival, 3-year survival, and 5-year survival. Survival rates vary considerably worldwide, but follow patterns that correspond to development and income level. In general, developed countries with high income levels experience approximately 80% survival, middle-income countries experience 60% survival, and low-income countries in less-developed regions experience approximately 40% survival as reported by the World Health Organization (2012). Low survival in developing countries is related to lack of early detection resources and inadequate diagnosis and treatment facilities (World Health Organization, 2012). Age differences in survival can also be seen; in breast cancer, five-year relative survival is best for women aged 40 to 79 years (87%-90%) while younger women and older women have lower relative survival, 85% and 79% respectively (Canadian Cancer Society's Advisory Committee on Cancer Statistics, 2015).

This study is most concerned with the experience of invasive breast cancer in the early portion of the cancer journey, or from diagnosis to one-year survival. Medically, these women will have experienced a diagnosis of invasive breast cancer and likely have faced decisions concerning initial treatment, adjuvant therapy and clinical follow-up. Joined with these, are a myriad of other possible decisions regarding physical, psychological, and social issues for these women.

Psychosocial Impact of Breast Cancer

The experience of a life threatening illness, such as cancer, requires a person to consider an array of emotional, medical, social, and existential demands (Sormanti, Kayser, & Strainchamps, 1997). The Institute of Medicine (Nancy E. Adler & Page, 2008) proposes that the illness and treatment of cancer has physical and psychosocial implications that, when cared for as a whole, contribute to whole-person cancer care (Nancy E. Adler & Page, 2008). While this concept was familiar prior to 2008, this statement has been an acknowledgement of the experience of the patient, as well as a call for whole-person care, with an emphasis on psychosocial care. Although psychosocial research is relatively young (Jacobsen, Holland, & Steensma, 2012), great strides have been made in creating awareness around the work of psychosocial professionals (Jacobsen et al., 2012). Gains have also been made in developing standardized tools to recognize indicators of psychosocial morbidity among patients with cancer (Keller et al., 2004), as well as evidence showing that appropriate psychosocial support can lead to improved health outcomes for the patient and economic benefit for the health system (Barry D. Bultz & Carlson, 2006).

Psychosocial Distress

Although many persons with cancer do not suffer from adverse psychosocial impact, approximately 35-45% of cancer patients experiencing psychosocial distress that require specialized and/or intensive interventions at any point in the cancer experience (B.D. Bultz, 2005; Vodermaier, Linden, & Siu, 2009; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Although “distress” is not a psychiatric term, it is useful for cancer clinicians, in that it is well understood by non-mental-health clinicians (Carlson, Waller, & Mitchell, 2012) and does not carry the stigma associated with diagnostic labels (Carlson et al., 2012). Psychosocial distress is defined as:

> “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears, to problems that can become disabling such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.” (National Comprehensive Cancer Network, 2014, p.5).

This definition suggests that psychosocial distress is broader than well-known major psychiatric disorders (i.e. depression, anxiety), and distress may be cancer-specific and/or present as generalized symptoms (Ganz, 2008).

It is known that the experience of diagnosis and treatment of breast cancer may result in considerable distress (Helms et al., 2008). It is also known that a diagnosis of invasive breast cancer propels women into a time of uncertainty (J. P. Nelson, 1996; Siegel et al., 1999) that brings fear (Stanton et al., 2002; Stephens, Osowski, Fidale, & Spagnoli, 2008) and emotional work (Coyne & Borbasi, 2006). This disease may challenges a woman's identity (Piot-Ziegler, Sassi, Raffoul, & Delaloye, 2010), self-esteem (Berterö, 2002; Hill et al., 2011), body image (Helms et al., 2008; White, 2000), and relationships (Mellon, 2002; Sormanti et al., 1997). However, even with these commonly felt distresses, most women adjust well to a breast cancer diagnosis and the treatments experienced, particularly if they do not experience a recurrence of cancer (Ganz et al., 2002). Protective factors for distress are shown to include supportive networks available to the diagnosed woman (Ganz, 2008) and professional resources provided by clinical staff (Ganz, 2008), including routine support and timely referrals to specialized services.

Although most women adjust well to breast cancer, an understanding the distress associated with the disease is crucial because the negative psychosocial impacts can be significant in the context of this disease (Linden, Vodermaier, MacKenzie, & Greig, 2012). Women that do experience distress due to breast cancer are at risk of distress accompanying them throughout the breast cancer journey, and impacting their long-term quality of life (Ganz, 2008; Stava et al., 2006; Waldrop, O'Connor, & Trabold, 2011; Zebrack, Yi, Petersen, & Ganz, 2008). Literature suggests pre-existing mental illness (Ganz, 2008), comorbid conditions (Ganz, 2008), low income (Zebrack et al., 2008), and low levels of instrumental support (Ganz, 2008) or emotional support (Ganz, 2008; Hill et al., 2011) are indicators of women being at an increased risk of psychosocial distress.

Psychosocial impact across the lifespan. Literature suggests that the psychosocial impact of any diagnoses of cancer may be different across the lifespan (Siegel et al., 1999). It has been reported that the diagnosis of cancer among young adults is associated with a new sense of vulnerability (Siegel et al., 1999). This causes emotional distress with younger adults who experience increased anger, fear, and anxiety because their world after diagnosis is felt to be unjust, unfair, unsafe, and uncertain (Siegel et al., 1999).

In the case of breast cancer, it is thought that younger women are at a higher risk of psychosocial distress than older women (Avis, Crawford, & Manuel, 2005; Ganz, 2008; Linden et al., 2012; Zebrack et al., 2008). It has been shown that, in the case of invasive breast cancer, the risk of depression and anxiety are inversely correlated with age (Cohen, 1999; Linden et al., 2012; Zebrack et al., 2008). That is, in breast cancer the younger cohort is at a higher risk of anxiety and depression during the cancer journey than is their older counterpart with the same disease (Linden et al., 2012). This may be due to the “off-schedule” or untimely aspect of being diagnosed with cancer at a young age (Revenson & Pranikoff, 2005). Young women with cancer experience worries about careers and finances (Shaha & Bauer-Wu, 2009) that are different from older women with breast cancer because young women are more likely to be at the beginning of careers and are less likely to have experienced financial stability as an independent. Further, younger women with breast cancer perceive their quality of life to be lower than older women as a result of breast cancer (Zebrack et al., 2008). This has been attributed to poorer emotional wellbeing, specific cancer-related concerns, depression, and intrusive thoughts for this younger cohort (Wenzel et al., 1999). Lower perceived quality of life may also be due to chemotherapy since young women are more likely to experience these toxic treatments than older women, leading to distresses such as memory loss (Stava et al., 2006).

Older women with breast cancer experience unique psychosocial impacts as well, and these psychosocial processes contribute to the nature and the management of their disease (Nussbaum, Baringer, & Kundrat, 2003). Older women have more health problems than younger women in survivorship, independent of receiving chemotherapy or not (Stava et al., 2006; Zebrack et al., 2008). In general, older breast cancer survivors experience overall better quality of life and mental health than their younger cohort (Zebrack et al., 2008), but they have poorer physical health (Zebrack et al., 2008) and health-related quality of life due to comorbid conditions (Robb et al., 2007; Zebrack et al., 2008). Another risk factor for increased psychosocial distress is low income (Zebrack et al., 2008), which may be particularly salient for older women whom are more likely to be on a fixed-income than their younger counterparts. However, literature suggests that a higher degree of psychosocial adaptation can be found among older women with breast cancer because these women have had more life experience, including prior experiences with the health care system (Ganz, 2008), witnessing the diagnosis of others with cancer (Ganz, 2008), and having fewer competing demands (Mor et al., 1994). It is thought that these contribute to coping and successful adaptation to disease (Ganz, 2008).

As the literature shows, it is known that women with invasive breast cancer are at risk of psychosocial distress that may have long-term consequences. It is also known that there are differences in the psychosocial impact of cancer on younger and older women and further descriptions of specific challenges are presented here.

Breast Cancer as a Challenge to Identity

The diagnosis of breast cancer disrupts the life narrative of diagnosed women (Collie & Long, 2005) through the introduction of images of pain, suffering, and death that come with a feared life-threatening disease (V. Lee, 2008). The “existential plight” of cancer begins as thoughts about mortality are raised and as the women questions previously-held belief systems (V. Lee, 2008). This disruption of events may prompt women to find a place for cancer in their lives (Vachon, 2001) through a search for meaning, which may be integral in how these women adjust to their diseases (Lethborg, Aranda, & Kissane, 2008; Vachon, 2001).

When studying how women acclimatize to breast cancer in the early portion of the cancer journey, it was found that the main concerns for these women were concepts connected to identity (Lally, 2009). Breast cancer threatens women’s self-integrity, including their bodily health, view of self, how others view them, and the loss of roles in the spheres of social settings, family and work. Identity is linked to self-schemas which are knowledge structures about the self (Markus, 1977). Self-schemas integrate and summarize experiences, and function as frameworks or structures (Markus, 1977; Stein, 1995) which become the foundation for thought and purposeful action of response (Stein, 1995). A person, including a woman with breast cancer, does not only hold one self-schema but, depending on her values, a myriad of self-schemas (Markus, 1977); these may be attached to any aspect of a person, including her physical appearance, social roles, personality traits, interests, and skills (Markus, 1977). In breast cancer research, sexual schemas (B. L. Andersen, 1999) and relationship schemas (Sormanti et al., 1997) are present. It is emphasized that these schemas are formed through culture and family of origin, and influence a woman's actions when her identity is challenged by the diagnosis of breast cancer (Sormanti et al., 1997). Negative self-schemas containing self-blame and shame (Hill et al., 2011) may occur in cancer and are highly associated with emotional distress (Hill et al., 2011).

Meaning-making in breast cancer. Identity and meaning of breast cancer are linked (Collie & Long, 2005). The restructuring of life after a cancer diagnosis calls for the new experiences and feelings brought forth due to cancer to be integrated into a revised self-narrative (Collie & Long, 2005). This process is referred to as meaning-making, and is "a fundamental human process that takes on special significance at times of crisis and life disruption" (Collie & Long, 2005).

Just as meaning-making has been emphasized as crucial in the overcoming of suffering (Frankl, 2006), meaning-making has similarly been viewed as integral to adapting to cancer, since enhancing a patient's sense of meaning mitigates potential depression, hopelessness and a desire for hastened death (Breitbart et al., 2010; Breitbart W, Rosenfeld B, Pessin H, & et al, 2000). Collie & Long (2005) examine meaning-making processes in relation to meaning in illness. The authors differentiate between global meaning (meanings of life in general), which may be stable and culturally determined, and situational meaning (meanings given to particular events). Illness meanings in breast cancer include concern, vulnerability and loss, personal empowerment, psycho-spiritual healing, and helping others (Collie & Long, 2005), and the authors explain that creating meaning from the experience of cancer can increase a woman's self-worth, renew her purpose in life, and increase her sense of interconnection to others. This occurs when the emotional and physical pain experienced in cancer leads to self-transcendence and a sense of purpose that provides meaningfulness. It is through positive meaning-making that some women experience a decrease in difficult emotions and move forward to realize new goals (Collie & Long, 2005).

Meaning-making is a social construction that is influenced by social interpretations such as the voices of scientists, women of privilege, and breast cancer activists (S. E. Thorne, 2000). These influences may be helpful for some, but may impede meaning-making for others (S. E. Thorne, 2000). Through this cognitive process of making-meaning, a woman may struggle to keep what is personally meaningful about her life before cancer (V. Lee, 2008). Collie & Long (2005) describe other factors which may obstruct meaning-making, including the inability to form intimate relationships, avoiding thinking about cancer, the absence of time for reflection, or not having the opportunity to talk about the experience or express oneself. These factors may be culturally derived or gendered when women feel silenced in their contexts of living, adding to the confusion for women working to develop meaning of their disease (S. E. Thorne, 2000). These are examples of social constructions that shape how women may make meaning and integrate meaning with her self-schemas relating to cancer (S. E. Thorne, 2000).

Identity across the lifespan in breast cancer. Little is understood about the differences between younger and older women in their construction of identity, or how they make meaning in the context of breast cancer. It is known that, for younger women, the diagnosis of cancer is shocking (Coyne & Borbasi, 2006) and is an opportunity to contemplate mortality (Shaha & Bauer-Wu, 2009) when death may not have been contemplated before. An untimely diagnosis alters the beliefs that the young woman has about herself and the world around her (Siegel et al., 1999), she feels a deep sense of a loss of control (Fisher & O’Connor, 2012), and the context may create emotional distress such as fear, sadness and anger (Siegel et al., 1999). Women with the identity of “mother” find that they may need to adjust or reconstruct their identity (Coyne & Borbasi, 2006; Fisher & O'Connor, 2012), while balancing the need to continue mothering and the need to be a patient (Fisher & O'Connor, 2012). Very little is known about the experiences of older women and their self-schemas and meaning-making. However, prior research shows that older women are more likely to approach their diagnoses in a matter-of-fact manner associated with the expected process of aging (Foley et al., 2006), and compare the difficulties of cancer to other challenging life experiences (Foley et al., 2006).

It is unknown how meaning making, identity, and social constructions may influence decision making in breast cancer. However, since self-schemas and meaning-making are foundational for action in response to decision making scenarios, there is a need to understand the social lives of women with breast cancer and how these interact with decision making.

Breast Cancer as a Challenge to Body Image

The concept of body image describes the level of investment a woman puts into her body image in determining her satisfaction, happiness, and wellbeing (Cash & Smolak, 2011). The disruption of body image in breast cancer is attributed to alopecia (hair loss) as well as changes in the breast and a woman's weight (Helms et al., 2008). Literature surrounding body image focuses on the breast in particular, since the physical breast carries a connotation of femininity, motherhood, and sexuality (Cash & Smolak, 2011). The disruption of the appearance of the breast may cause distress for many women with breast cancer, effecting her emotional wellbeing and self-concept (Helms et al., 2008). However, it has also been found that a premorbid concern about any body image issue can contribute to distress among women with breast cancer (Helms et al., 2008).

Distress may be attributed to the changing body representing a physical and persistent signal of cancer to the diagnosed woman, as well as to others who view the changed body (Rasmussen, Hansen, & Elverdam, 2010).

Women with breast cancer who face the choice of mastectomy may consider breast reconstruction as a method of ameliorating some of the challenges associated with body image. Research is inconclusive as to whether body image predicts the choice of mastectomy versus breast conservation therapy or the choice of breast reconstruction after mastectomy. However studies show younger women do seek normality in their breasts following mastectomy (Fang, Balneaves, & Shu, 2010) and seek breast reconstruction more often than older women (C. N. Lee & Foster, 2006). Women who undergo breast reconstruction do not identify themselves with the Western socio-cultural understanding of plastic surgery, nor do they identify with women who undergo cosmetic beauty surgery (Lammer et al., 2007). Rather, women who undergo breast reconstruction consider reconstructive surgery as a therapeutic option to enable them to appear as they had before cancer (Fang et al., 2010). However, when women are unprepared for the changes that breast reconstruction cannot reverse, they struggle to accept their new breasts even with reconstructive surgery (Fang et al., 2010).

Body image as more than appearance in breast cancer. “Body image” may encompass more than appearance since women are also concerned with how their bodies function and feel after breast cancer (Campbell-Enns & Woodgate, 2013; Carver et al., 1998; Zimmermann, Scott, & Heinrichs, 2010). Body image includes appearance, body integrity (intactness), sense of wholeness, and normal functioning (Carver et al., 1998), which may include concerns over sexuality and losses in fertility (Snyder & Tate, 2013) and sexual function (B. L. Andersen, 1999).

As well, women with cancer who are mothering young children are not only concerned with how their children view their changed body, but how their bodies function so that they can maintain their "normal" mothering activities (Campbell-Enns & Woodgate, 2013; Coyne & Borbasi, 2006; Fisher & O'Connor, 2012). Since touch between mother and child is integral in their attachment and relationship, mothers with cancer are also concerned that their bodies feel "normal" for their children (Campbell-Enns & Woodgate, 2013). As a result, the loss of a breast through mastectomy threatens the mother-child bond because mothers may fear that her relationship with her children will change when the children touch her altered body where her breast had been (Campbell-Enns & Woodgate, 2013).

Body image across the lifespan in breast cancer. The meanings of body image in breast cancer may vary due to the age and/or life stage of the woman experiencing cancer (Fallbjörk, Karlsson, Salander, & Rasmussen, 2010). Many young women experience problems with body image and/or sexual problems in the first year of breast cancer treatment (Fobair et al., 2006). Fobair et al. (2006) interviewed women in relationships and determined that more than half of the sample of women were concerned with physical appearance (e.g. problems associated with mastectomy/reconstruction, alopecia, weight changes), sexual function (vaginal dryness), and/or other problems (lack of sexual interest, mental health, self-esteem, partner's ability to understand the woman's feelings).

Also, as cited earlier, mothers have specific body image concerns in cancer, however when young women are not mothering they experience other losses that have great psychosocial impact, losses that are largely related to the function and feel of their bodies. Early menopause symptoms due to cancer treatments are significant and untimely concerns for younger women (Coyne & Borbasi, 2006; Snyder & Tate, 2013). Younger women diagnosed with breast cancer experience distress related to vaginal dryness affecting sexual function (Avis et al., 2005), interrupted childbearing (Canada & Schover, 2012; R. J. Lee et al., 2011; Siegel et al., 1999), or infertility (Canada & Schover, 2012; Ganz, 2008; Gorman, Usita, Madlensky, & Pierce, 2011; Thewes et al., 2005). Although younger women with breast cancer welcome honest discussions about fertility at diagnosis (R. J. Lee et al., 2011), research shows that these women have low levels of knowledge about fertility and breast cancer (Peate et al., 2011). Little knowledge is associated with decisional conflict and undermines the quality of treatment decision making (Peate et al., 2011).

Regarding older women with breast cancer, little is known about specific body image concerns experienced. It is known that older women with cancer experience body dissatisfaction and may experience higher levels of dissatisfaction than younger women, possibly due to more persistent problems with the physical functioning of their body (Zimmermann et al., 2010). Whether these problems are a result of cancer, or from comorbidities that come with aging, is unknown.

It is largely unknown how body image issues intersect with decision making in breast cancer across the lifespan. We know that younger women tend to choose breast reconstruction, a surgery thought to be related to body image concerns. We also know that there is a need for improved information so that young women with breast cancer can better navigate issues regarding their bodies (Gorman et al., 2011), yet the needs of older women are undetermined. Understanding the distress associated with body image across the lifespan may enable a better understanding of the decision making experience for all women with invasive breast cancer.

Breast Cancer as a Challenge to Relationships

It is also known that the diagnosis and treatment of breast cancer affects relationships including spousal relationships (Zahlis & Lewis, 2010), relationships with children (Bell & Ristovski-Slijepcevic, 2011; Elmberger, Bolund, Magnusson, Lützén, & Andershed, 2008; Fisher & O'Connor, 2012), and older parents (Raveis et al., 2010).

Impact of cancer on the family. The bidirectional nature of family relationships (Kuczynski, 2002) contends that it is not only the diagnosed person who is impacted by the disease; as a woman with breast cancer experiences vulnerabilities, so too does her family (Awadalla et al., 2007). Literature regarding family caregivers of cancer survivors reveals the quality of life of family members is lower than survivors (Mellon, 2002), and family members experience higher fear of cancer recurrence and less support than diagnosed family members after one year of cancer survivorship (Mellon, Northouse, & Weiss, 2006). It has also been shown that there is a higher degree of coping through the use of drugs and alcohol for family caregivers of breast cancer survivors in comparison to the survivors (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004). Finally, just like the diagnosed women, family members also strive to make meaning of cancer through the context of family life (Mellon, 2002).

The event of breast cancer entering the family challenges relationships (Fergus & Gray, 2009; Zahlis & Lewis, 2010). Spouses and partners of women with breast cancer work to adjust roles and to balance added household responsibilities, particularly during times of treatment (Northouse, 1992). Literature states that partners find the period of time closest to diagnosis to be highly stressful (Northouse, 1992; Zahlis & Lewis, 2010). Partners are concerned with managing the stress in their relationship during breast cancer

(Shands, Lewis, Sinsheimer, & Cochrane, 2006), including the stress associated with the threat of the disease (Shands et al., 2006), the effect of the disease on their children (Shands et al., 2006; Zahlis & Lewis, 2010), and needing to be together (Shands et al., 2006). Despite the felt stress, couples also tend to recognize the potential to strengthen their relationships during the cancer experience (Fergus & Gray, 2009; Zahlis & Lewis, 2010).

Children of women with breast cancer are impacted by changes in the level of interactions with their mothers (Faulkner & Davey, 2002), with increased positive mother-child interactions associated with the increased wellbeing of family members (Faulkner & Davey, 2002). On the other hand, children are impacted negatively by a negative change in the mother's mood or marital tension (Faulkner & Davey, 2002). While children manifest distress uniquely (Beale, Sivesind, & Bruera, 2004), children typically display emotional symptoms in generalizations according to the child's age, sex, and the sex of the parent with cancer (Faulkner & Davey, 2002). It has been found that it is the adolescent daughters of mothers with cancer that are at the highest risk of psychosocial distress (Faulkner & Davey, 2002). Further, when a parent is dying as a result of cancer, it has been shown that children have a good understanding of their parents' disease (Beale et al., 2004) and timely interventions can help these children cope with their distress (Beale et al., 2004).

Parents of women with breast cancer are also faced with the early timing of their daughters' diagnoses (Raveis et al., 2010). There is no literature to be found about fathers of women with cancer at this time, but a small number of studies explain that mothers of women with breast cancer experience psychosocial distress and an intense feeling of responsibility for their daughters' health and wellbeing (Raveis et al., 2010). Mothers of women with breast cancer may experience a resurgence of maternal behavior (Raveis et al., 2010) as they witness their daughters struggle with the disease and its treatments. This distress does not go unnoticed by their daughters with cancer, and as the distress of the daughter is closely related to the distress of their mother (Baider, 2008).

Relationships and the diagnosed woman. For women with cancer, relationships have a role in coping (Tighe, Molassiotis, Morris, & Richardson, 2011), making sense of the illness experience (Tighe et al., 2011), and the psychosocial adjustment to the disease (Kayser & Sormanti, 2002). In a study comparing women with breast cancer to men with prostate cancer, it was shown that women were more likely to want to connect with others and openly express their emotions than men (Rager, 2007). This study was conducted from a gender perspective and it provides reason to consider that women connect to others differently than men in cancer, and yet more information is needed to understand these needs for women.

Family relationships are vital for women with cancer because these relationships provide a high degree of social support (Snyder & Pearse, 2010), including emotional, tangible, informational, and experiential support (Snyder & Pearse, 2010). In the early cancer journey, women with breast cancer work to balance their support needs while waiting for surgery (Dickerson, Alqaissi, Underhill, & Lally, 2011). This includes accepting care from others while nurturing others (Dickerson et al., 2011). In some circumstances, this leads to a diagnosed woman showing care by self-sacrificing (Kayser & Sormanti, 2002), which is inversely correlated with the care a woman takes for her own health (Kayser & Sormanti, 2002).

Self-silencing is the phenomenon of silencing or supressing thoughts, feelings and actions to avoid conflict, ensure safety, or to maintain a relationship (Jack & Ali, 2010).

While self-silencing may enable a woman to reach these goals regarding relationship and safety, self-silencing can also lead to diminished sense of self, shame, desperation, and anger (Jack & Ali, 2010). In the context of illness, research has shown that women with breast cancer experience much emotional work in disclosing cancer information with those they are in close relationship with (Yoo, Aviv, Levine, Ewing, & Au, 2010). Communicating with loved ones in cancer demands a balance between telling the truth and protecting others (Billhult & Segesten, 2003; Campbell-Enns & Woodgate, 2013; Dickerson et al., 2011), resulting in women balancing worries about loved ones with the task of educating and instructing family (Campbell-Enns & Woodgate, 2013; Yoo, Aviv, et al., 2010). Research shows that open communication is associated with better mental health outcomes in breast cancer (Mallinger, Griggs, & Shields, 2006) and, although the majority of women can communicate openly about their breast cancer with family members (Mallinger et al., 2006), there is a complexity to this interaction as family members undertake emotional work to confront the cancer experienced by their loved one (Baider, 2008). As a result there is a need for negotiation and accommodation when it comes to communicating cancer information in the family (Baider, 2008), yet it is unknown if the construct of self-silencing is influential in decision making in the context of breast cancer.

Studies show that supportive relationships change or diminish over time in the breast cancer journey (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007). Support is highest soon after diagnosis and decreases significantly within the first year of the cancer journey (Arora et al., 2007). When survivors of breast cancer consider themselves lonely, Rosedale (2009) describes that these women feel alone in being aware of their mortality, the experience of ongoing symptoms, a change in their identity, and a change in their threshold for distress. Loneliness is a problem for some women with breast cancer because, while they feel strongly connected to their loved ones and to the suffering of others, they perceive these connections as fragile (Rosedale, 2009).

Relationships across the lifespan in breast cancer. Literature shows family relationships are improved for both younger and older breast cancer survivors (Stava et al., 2006), however it is thought that the intimate relationships of younger women that are more likely harmed in the context of breast cancer survivorship (Stava et al., 2006). Younger adults with cancer may experience increased loneliness (Rosedale, 2009) and a greater sense of isolation from peer and support networks (Davis et al., 2008; Siegel et al., 1999) than older adults, because they perceive themselves to be different from their peers as a result of cancer (Siegel et al., 1999). This is critical in light of research suggesting that higher social isolation (Kroenke et al., 2013) and lower social connectedness (Beasley et al., 2010) may be associated with higher overall mortality, yet these associations need further exploration and are dependent on the quality of relationships, are unrelated to breast-cancer specific mortality (Kroenke et al., 2013) and may differ depending on cancer type (Helgeson & McUmber, 2010).

Younger adults with cancer are more likely than older women to be in new or no intimate relationships (Adams et al., 2011), yet there is limited research on the impact of breast cancer on women who are not married or partnered. From what can be found, unmarried women face unique challenges including fear of rejection (Corney, Puthussery, & Swinglehurst, 2014; Gluhoski, Siegel, & Gorey, 1998), pessimism regarding future relationships (Gluhoski et al., 1998), perceived desirability (Gluhoski et al., 1998), inadequate support (Corney et al., 2014; Gluhoski et al., 1998), fertility concerns (Corney et al., 2014), and feelings that precious time has been lost (Corney et al., 2014). This is in comparison to young partnered women who, when the relationship is of good quality and relatively free of conflicts, experience greater support. However, these women also feel a high degree of guilt for bringing cancer into their marriages and for the toll that the disease takes on the partner (Siegel et al., 1999).

Younger women mothering children during cancer experience distress due to concurrent demands (Zebrack et al., 2008). These demands stem from the felt need to care for others while they experience treatment and needing to recover (Kim, Ko, & Jun, 2012). This is, in essence, the need to protect oneself while preserving mothering at the same time (Stiffler, Haase, Hosei, & Barada, 2008). Mothers with cancer strive to be “good” mothers (Elmberger, Bolund, & Lützén, 2005; Helseth & Ulfsaet, 2005) as determined by her own social and cultural background (Bell & Ristovski-Slijepcevic, 2011). However, being a “good” mother in Western society is in conflict with being a patient (Dent, 2006). This conflict impacts family relationships (Coyne & Borbasi, 2006; Elmberger et al., 2008) of young women as families as they work to maintain a sense of normality (Bell & Ristovski-Slijepcevic, 2011; Helseth & Ulfsaet, 2005), even when mothering is interrupted by the disease (Elmberger et al., 2005).

During the aging process the dominant relationships in the lives of women with cancer may change (Nussbaum et al., 2003). At different times in adult life, different relationships take centre stage – be it parent-child, marital, friendships, or sibling relationships (Nussbaum et al., 2003). As a younger person, a diagnosed woman may have a large circle of support comprised of family, friends, colleagues, and neighbours. As persons age beyond 65 years they tend to have less frequent interactions with persons who are not in their most intimate circle, a circle which may be comprised mainly of family and health care providers (Nussbaum et al., 2003). It is argued here that cancer changes the nature or dynamics of all relationships, but it is a salient point that, for older women with already diminished social interactions and social support, cancer poses a unique psychosocial risk – cancer may cause changes to relationships within an already smaller supportive network (Nussbaum et al., 2003). It is reported that their family and intimate relationships are improved in cancer survivorship for older women (Stava et al., 2006), although it is unclear if this applies to women whom are not partnered.

The bidirectional nature of family relationships put vulnerable family members at risk of distress in the context of cancer. It is also known that supportive relationships can protect women with breast cancer from psychosocial distress. However, issues of self-sacrificing, self-silencing and loneliness can predict poor quality of life for women with breast cancer. Younger and older women experience relationships and the associated stresses differently in the context of breast cancer. At this time, it is unknown how significant relationships contribute to the decision making process for women with breast cancer across the lifespan.

Decision Making in Cancer

Decision making is a cognitive process that is fundamental to all aspects of cancer care (W. Nelson et al., 2005). Throughout the cancer journey, many decisions must be made which affect the wellbeing of the person with cancer and their surrounding community (Fischhoff, 2005). This wellbeing does not only depend on the final decision made but also on the act of decision making (Fischhoff, 2005; Halkett, Arbon, Scutter, & Borg, 2005).

Medical, or health decision making, is a relative young field (Davies et al., 2010) that stems from various disciplines such as economics, psychology, mathematics, and linguistics (Davies et al., 2010; Fischhoff, 2005). Fischhoff (2005) asserts there is a clash of paradigms between traditional decision making and health decision making. In reading decision making literature, moving from the discourse of psychosocial oncology to medical decision making can feel like a clash of paradigms as well. In health decision making research, the language changes from psychosocial oncology's use of "risk" to medical decision making's use of "cost" or "gamble." Those within the discipline of psychosocial oncology may use the terms "values" and "distress," where those within medical decision making might use "biases" and "decisional conflict," respectively. Further, decision making research has compiled terms that include: expected utilities, trade-offs, frames, decision rules, rationality, and context effects. These are used infrequently in psychosocial oncology, and yet those within psychosocial oncology and medical decision making disciplines seek to describe the same health events. Several terms are used between the disciplines, chief among these are "uncertainty", "preferences", and "outcomes."

In a general sense, health decision making research is categorized as either clinical or patient decision making. This study is interested in patient decision making although it is recognized that the areas overlap. Another division in decision making literature is between normative versus descriptive decision making. Normative decision making is derived from traditional decision making theory which identifies the optimal choice (Fischhoff, 2005) in a given situation that is both expected and "rational," according to experts in the field rather than persons experiencing illness. Most decision making tools for patients in cancer are built upon normative thought (W. Nelson et al., 2005) which, accordingly, is built on the underlying assumption that all persons approach decisions as expected (Stanton et al., 1998). On the other hand, descriptive decision making acknowledges that persons in the real world do not always follow the normative rules or models based on rationality (Davies et al., 2010; Fischhoff, 2005), and therefore persons may make decisions that are perceived as “irrational” by others (W. Nelson et al., 2005). This has been found to be common in cancer, where decision making may be both urgent and potentially life-altering (Davies et al., 2010).

Where there is a gap between normative and descriptive decision making, or what is expected and what actually occurs in cancer decision making, patients are known to be motivated to action by their values and beliefs rather than rational choice (Campbell-Enns & Woodgate, 2013; McCaul, Peters, Nelson, & Stefanek, 2005). Persons with cancer may over or underestimate the extent to which their choices are influenced by their affect in-the-moment (Davies et al., 2010; Loewenstein, 2005; Ubel, Loewenstein, Schwarz, & Smith, 2005), just as health care providers can underestimate the impact of those feelings on their patients (Loewenstein, 2005).

When studying the differences between clinician and patient preferences in cancer, it was determined that clinicians judgements did not correspond closely with their patients and should not be used as substitutes for patient choice (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). Yet a study of patients making decisions in head and neck cancer (Davies et al., 2010) reveals when symptoms and problems interfere with the ability to choose, it is the trust and confidence in the health care provider that helps patients decide. This trust may be a coping function or a way of seeking social support, enabling a person with cancer to reduce the decisional conflict generated by the situation (Luce, 2005).

Fischhoff (2005) contends that doing descriptive research in cancer focuses on the understandings of the patient and identifies the issues that are most important for them.

Descriptive work is the goal of this study, that is, to explore the experiences of decision making for women with breast cancer. In descriptive decision making research, what is a “good” decision is different from normative research. Rather than the clinically optimal choice preferred in normative models, a “good” decision in descriptive research is a decision that considers the individual needs, values, and preferences of the persons involved (Davies et al., 2010). This connects strongly to psychosocial oncology in that a descriptive study of decision making in cancer is patient-centered.

Blank et al., (2006) suggest that there are major differences and commonalities to note in treatment decision making across cancer diagnoses. Major differences in the decision making experience are due to emotional, personal, and social contexts. These include the age of the patient, the complexity of decisions, the desire for participation in decision making, and the desire for information (Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006). Still commonalities do exist, including the importance of the patient-provider relationship, patient-provider communication, decisions with uncertainty, and the internet as a developing source of information for patients (Blank et al., 2006). No further research can be found to address the differences in the decision making process for younger or older persons with cancer in general. In order to promote psychosocial wellbeing and whole-person care, more research is needed to address how patients experience decision making across the lifespan. The focus of this study is women with an invasive breast cancer diagnosis, therefore breast cancer literature will be reviewed here in an effort to describe breast cancer-specific decision making.

Decision Making in Breast Cancer

The decision making process in breast cancer is a complex process which many women find difficult (Katz & Hawley, 2007). Treatment decisions may involve rapid choices regarding surgery, radiation therapy, chemotherapy, and hormone therapy, all of which may have a range of effects on the woman and her family (Katz & Hawley, 2007). Women report that the process of treatment decision making begins soon after diagnosis (O'Brien et al., 2008). These decisions are of great significance to a woman's psychosocial wellbeing in that her initial experiences with breast cancer may shape her future fears about recurrence (Revenson & Pranikoff, 2005). Decision making experiences in the context of breast cancer are also known to be related to long-term satisfaction (Lantz et al., 2005), quality of life (T.F. Hack, Degner, & Dyck, 1994), and well-being (Deadman, Leinster, Owens, Dewey, & Slade, 2001).

Research suggests that the process and execution of decision making may be as important as the actual decision made (Halkett et al., 2005; Katz & Hawley, 2007), because the act of decision making may affect women's understanding of themselves (Halkett et al., 2005). The impact of decision making on the feeling about the self for women was also highlighted by a study from a gender perspective (Granek & Fergus, 2012). This study showed that women noticing changes in their breast prior to diagnosis, made cancer screening decisions due to social, cultural and historical discourses. When decisions were counter to what was expected, women were viewed as irresponsible and this led to feels of shame for women (Granek & Fergus, 2012). Decisions may define women with breast cancer since they continue to relive their decisions through daily reminders, or through the presence of the threat of cancer in their lives. These are continued reminders of the decision making experience (Halkett et al., 2005).

In breast cancer, cognitive and emotional factors are at play in decision making (Katz & Hawley, 2007). However, it has been shown that women with breast cancer feel like circumstances are not in their control immediately after diagnosis, including their decisions (Fang, Shu, & Fetzer, 2011; Halkett et al., 2005; Temple et al., 2006). This loss of control is associated with an increase self-doubt and decreasing feelings of self-worth (Halkett et al., 2005). Lack of control may affect a woman's level of preparedness for decision making early in the cancer journey, influencing adaptation to the disease (López, López-Roig, & Pastor, 2007). That said, newly diagnosed women do attempt to ready themselves for future challenges and decisions (Halkett et al., 2005), but if they were unable to get to a state of readiness, women were more likely to feel unprepared, less communicative with health care providers, and be less accepting of their diagnosis and need for treatment than women who were ready for decision making (Halkett et al., 2005). It is possible that physical symptoms also influence decision making later in the breast cancer experience, as is the case in head and neck cancer (Davies et al., 2010), but there is no research found at this time to support this hypothesis.

Treatment decision making in breast cancer. In the case of breast cancer, treatment usually begins with a surgical decision and often leads to adjuvant treatment, including chemotherapy and/or radiation. Little is known through literature about the experience of decision making regarding adjuvant treatment. Scant research available shows that women with breast cancer find discussions with their surgeons and family physicians about adjuvant treatment are important in their decision making even when these discussions are prior to their consultation appointments with a medical oncologist

(O’Brien et al., 2008). When considering chemotherapy options, women found numerical information regarding recurrence rates and side effects helpful in decision making as well as recommendations from their health care providers (O’Brien et al., 2008). Research has also shown that fear of radiation therapy and geographical distance from cancer centres may lead women to choose a mastectomy over breast conservation surgery (Boscoe et al., 2011).

Much of the breast cancer decision making literature addresses decisions regarding surgical treatment. Most early breast cancer treatment decisions begin with complex decisions between surgical options, namely various types of breast conservation treatment or mastectomy (with or without reconstruction). In the case of early stage breast cancer, breast conservation treatment is endorsed as the standard treatment (Han et al., 2011) and yet the number of women who undergo bilateral mastectomy is more than what would be expected based on medical criteria alone (Collins et al., 2009; Han et al., 2011). Moreover, the rates of contralateral prophylactic mastectomy have increased when women could be electing breast conservation surgery (Gollop, Kyle, Fancourt, Gilkison, & Mosquera, 2009; Han et al., 2011; King et al., 2011; Morrow & Pusic, 2011; Yi et al., 2010).

Survey research shows that differences in surgical decision making may be influenced by the patient’s age (Staradub et al., 2002), disease stage (Sariego, 2010), perception of best chance of survival (Fang et al., 2011; Gorman et al., 2011; Lam, Fielding, Ho, Chan, & Or, 2005), worries about recurrence (Adachi, Ueno, Fujioka, Fujitomi, & Ueo, 2007; Collins et al., 2009; Halkett et al., 2005; Lally, 2009; Lam et al., 2005; Molenaar et al., 2004), familial cancer experiences (Han et al., 2011; King et al., 2011; Lally, 2009; Yi et al., 2010), ethnicity (Tuttle, Habermann, Grund, Morris, &

Virnig, 2007; Yi et al., 2010), an aversion to radiotherapy (Collins et al., 2009; Halkett et al., 2005; Molenaar et al., 2004), agreement with the perceived preference of the physician (Lam et al., 2005; Molenaar et al., 2004), and access to immediate reconstruction (Han et al., 2011; King et al., 2011; Yi et al., 2010). Other psychological factors are cited such as self-efficacy (Adachi et al., 2007), cultural beliefs (Fang et al., 2011; J. A. Nelson, Nelson, Tchou, Serletti, & Wu, 2012), and body image concerns (Boehmer et al., 2007; Han et al., 2011; King et al., 2011; Kraus, 1999; Yi et al., 2010). Qualitative studies show that women with breast cancer base their preferences on the information they gather prior to their surgery consultation (Lally, 2009), perceived knowledge about the treatment (Lally, 2009), personal values and beliefs (Boehmer et al., 2007; Campbell-Enns & Woodgate, 2013; Lally, 2009), and a feeling that a specific option would suit their needs best (Campbell-Enns & Woodgate, 2013; Lally, 2009) which may be driven by intuition and/or emotions (Lam et al., 2005). Similarly, a qualitative study conducted from a gender perspective found that women’s value systems and body image shape the identity of womanhood and influence the surgical choices of women in breast cancer (Boehmer et al., 2007).

Patient-physician communication in breast cancer. Patient-physician communication is prominent in breast cancer decision making literature. As women with breast cancer struggle with the shock of a new diagnosis (Caldon et al., 2011), and are at a time of increased vulnerability (McWilliam, Brown, & Stewart, 2000), they are often forging a bond of connectedness with their physician (Phillips-Salimi, Haase, & Kooken, 2012). Phillips-Salimi et al. (2012) suggest that, optimally, connectedness between patient and physician is a relationship of reciprocity that includes caring, empathy, trust, respect, and an intimacy that comes with a sense of belonging. As patients experience inner struggles (Lammer et al., 2007), the patient-physician relationship can minimize distress during this time (Fallowfield, 2008). Through communication with their physicians, women view themselves positively through the eyes of their physicians (Lammer et al., 2007).

Patients have a preferred involvement in decision making (Katz & Hawley, 2007), and communication outcomes are enhanced when physicians are attentive to the preferred involvement of the patient (T.F. Hack, Degner, & Parker, 2005). When women achieve their preferred involvement in decision making, regardless of the level of involvement, they are more satisfied with surgical choice despite treatment type (Katz & Hawley, 2007), and emotional distress was decreased soon after surgical treatment (B. A. Vogel, Leonhart, & Helmes, 2009). It has also been shown compassionate and honest communication about benefits and prognosis enable women to make informed decisions when women with advanced breast cancer are making decisions about palliative treatment (Grunfeld et al., 2006).

Decision making theory in breast cancer. This review revealed a paucity of theoretical understanding regarding patient decision making in the breast cancer context. One definition of decision making, one decision making model, and one framework have been found. Katz & Hawley (2007) explain that “high-quality decisions can be defined as one that is fully informed and is consistent with the decision-maker’s underlying values.” (p.764) This definition conforms to the descriptive understanding of decision making and is suited to patient-centered care but the authors do not relate this definition to decision making theory development.

Balneaves & Long (1999) propose a model of decision making in the context of illness utilizing examples from breast cancer. The authors combine decision making theory with stress and coping theory to suggest a model titled the “embedded decisional model of stress and coping” (Balneaves & Long, 1999), however this model is not built upon the patient perspective.

Revenson & Pranikoff (2005) suggest a contextual framework to consider breast cancer decision making in which decision making is a method of coping with illness. This approach highlights the reasons for variation in decision making among patients with breast cancer as variation is attributed to sociocultural variables, the situational context, the interpersonal context, and the temporal context (i.e. the timing of the illness in life) (Revenson & Pranikoff, 2005). This contextual approach equating decision making as coping has been utilized in health research beyond oncology and may be useful in this context as well. However, the concept of decision making may be more than a coping strategy in cancer and must be investigated further.

Decision making across the lifespan in breast cancer. Regarding the influence of age on decision making for women with invasive breast cancer, literature can be found that focuses on surgical treatment decision making. Research shows that women choosing bilateral mastectomy or contralateral prophylactic mastectomy over breast conservation surgery tend to be younger (Han et al., 2011; Jackson, Camacho, Levine, Anderson, & Stewart, 2008; Molenaar et al., 2004; Sariego, 2010; Staradub et al., 2002; Tuttle et al., 2007; J. E. Vogel et al., 2011), but it is unclear as to why the younger cohort prefers this treatment route.

Beyond breast conservation surgery or mastectomy decision making, it has been shown that younger women with breast cancer are also more likely to undergo breast reconstruction when opting for a mastectomy than older women. Reasons for this trend are also unclear (C. N. Lee & Foster, 2006), but some authors speculate that this decision may be motivated by a younger woman's concept of risk management (J. E. Vogel et al., 2011) and worry about recurrence (Lally, 2009), her ethnicity (J. A. Nelson et al., 2012), and having fewer comorbidities than older women which may limit reconstruction options (C. N. Lee & Foster, 2006). It may also be due to physician bias, meaning that physicians may be more inclined to discuss breast reconstruction options with younger women (Alderman, Hawley, Waljee, Morrow, & Katz, 2007). This is important considering women are four times more likely to consider mastectomy over breast conservation surgery if they are educated about reconstruction options (Alderman et al., 2007).

Considering adjuvant treatment, rates of radiation and chemotherapy among older women continue to be lower than rates among younger women (Bernardi et al., 2008). It is generally thought that women of an older age have more comorbidities (Hurria et al., 2003) and thus the risk to quality of life does not outweigh the possible benefits of these toxic treatments (Bernardi et al., 2008). However older women have been shown to tolerate adjuvant chemotherapy equally as well as younger women even when considering comorbidities (Tallarico, Figueiredo, Goodman, Kreling, & Mandelblatt, 2005). It may be likely that the perceptions of both the health care providers and older women influence adjuvant treatment decisions in this age group (Tallarico et al., 2005).

Research focusing on age and the psychological or social impact of cancer on the process of decision making cannot be found at this time apart from the thesis study which serves as a pilot for this proposal (Campbell-Enns & Woodgate, 2013). This thesis study began the process of generating a theoretical understanding in decision making among mothers with cancer, all young women. The majority of the mothers had breast cancer and this group of young women described health and social decisions to be inseparable.

These women did not separate their social worlds from health decisions. In the final analysis, all of the young women were motivated in their decisions by their desire to maintain their bonds with their children. This theory development is in its infancy and yet there are lessons to be learned, chief among them is that young women with breast cancer may be motivated in their decision making by their values, relationships and the psychosocial threat that cancer brings to their lives. Further investigation is warranted to explore these concepts more fully.

Variation in communication patterns among women across the lifespan also appear in the literature. Allen et al. (2001) assert that younger women with breast cancer have a desire for more information than their older cohort, and are more likely to reject physician paternalism amid medical uncertainty than older women. Older women with breast cancer tend to feel that they have a high degree of control over their treatment decisions even with physicians play a substantial role in decision making (Stanton et al., 1998). This may be due to the feelings of trust developed with health care providers (Swainston, Campbell, van Wersch, & Durning, 2012), but it is uncertain. Also, women have preferred roles in decision making (Allen, Petrisek, & Laliberte, 2001; T.F. Hack et al., 1994; C. N. Lee & Foster, 2006; Nekhlyudov et al., 2005) but it is unclear if younger and older women have preferences as a result of their ages (T.F. Hack et al., 1994; Kadmon, Pierce, & Antonakos, 2012; Nekhlyudov et al., 2005; Swainston et al., 2012).

The Psychosocial Impact of Breast Cancer on Decision Making

Several experiences in cancer are not tied closely to psychosocial care research, among these is the experience of decision making. As this literature review explained, health decision making research resides primarily within the medical domain, specifically in the domain of treatment decision making. While this research is crucial, it rarely draws on the patient experience. Since decision making has a potentially large impact on survival and psychosocial outcomes, it is essential to consider psychosocial factors when studying the decision making process of women with breast cancer.

The psychosocial aspects of breast cancer may have consequences on decision making throughout the cancer journey, but is largely unknown if the experience of decision making in early cancer is impacted by psychosocial factors, or if breast cancer-specific distress interferes with decision making. Studies from a gender perspective are few, but these studies have shown that women connect with others differently than men in cancer, and that women are influenced by their social understandings, values, and body image. Furthermore, little is known about how a woman's age contributes to decision making when she has an invasive breast cancer diagnosis. Younger and older women with breast cancer experience differences in the psychosocial aspects of their disease including identity and meaning-making, body image, and relationships. Younger and older women also show that they respond to treatment options differently, and may choose non-normative treatment options which differ from preferred treatment practices.

It remains unclear as to how psychosocial factors influence decision making across the lifespan in the context of breast cancer. A greater understanding is needed of the experience of decision making across the lifespan in the context of breast cancer. It is the *experience* of decision making in breast cancer that requires further study in order to uncover the real-world decision making that occurs in this context. By paying close attention to the psychosocial impacts of the disease for younger and older women, crucial understanding will be gained to allow the unmet decision making needs of this group to be identified. In this way, the gap between what is expected and what truly occurs in decision making will be more fully understood.

Summary of the Literature Review

This literature review has provided an overview of current research pertaining to the psychosocial impact of breast cancer, as well as decision making in the context of breast cancer. While there is an expanding body of psychosocial research regarding patient distress in cancer, the reviewed literature demonstrates that there is minimal patient decision making research in breast cancer seeking to incorporate the psychosocial impacts of the disease. Decision making research has primarily concentrated on normative decision making, which has become the basis of decision making interventions aimed at patients. Where there are gaps between what is expected in decision making and what actually occurs in real life, there are few studies which seek to understand the experience of decision making in the highly complicated context of the early breast cancer experience. Moreover, where literature shows that there is a variation in women’s experiences in breast cancer due to their age, few studies attempt to compare the experience of women with breast cancer across the lifespan. This literature review provides support for the need to further study the experience of decision making in order to create an improved understanding of decision making for women with breast cancer across the lifespan.

CHAPTER 3: STUDY DESIGN

Where quantitative research looks to provide detailed understandings of the "what", "where" and "when" of health decision making, qualitative research can answer the "why" and "how" patients decide. Learning more about why and how patients decide is integral to understanding decision making in the context of health and illness. Without this understanding, it is difficult to provide timely and satisfactory support to patients and their families at various decision making points. Further, as a person-centred approach to health care becomes increasing valued by patients (Stewart, 2001), qualitative decision making research can fill gaps in our understanding regarding the *why* and *how* patients make their decisions. This may facilitate further steps toward informed patient decision making and better overall health outcomes within our health systems.

Despite the known benefits, qualitative research is not as common as quantitative research and, generally, it is less well understood as a methodology in certain areas of study (Crotty, 1998). For example, of the existing published qualitative studies in health decision making, most describe the research as "qualitative" without providing further details regarding the finer points of the components of the qualitative work. However, there are frameworks to aid researchers in the development of robust qualitative research (Carter & Little, 2007; Crotty, 1998; Wener & Woodgate, 2013). Of note, Michael Crotty (1998) put forward a framework for qualitative research which utilizes four elements – methods, methodology, theoretical perspective, and epistemology – to aid in organizing research by providing the stability and direction in the design process. Crotty's framework is a useful point of departure for researchers when embarking on topics which lend themselves to a qualitative research design. Each of the elements of Crotty's research framework is presented here, beginning at epistemology and moving toward methods.

Epistemology

Epistemology is the philosophical basis that addresses knowledge and what it means to know. Considering the epistemological standpoint of the researcher (and research) is crucial in the design process, since each epistemological stance "implies a profound difference in how we do our researching and how we present our research outcomes" (Crotty, 1998, p.9). This step in the design process was a reflective, creative endeavor that occurred while maintaining a solid connection to the research purpose. Ontological issues may come into play at this point as well, as understandings of the nature of being, becoming or reality are considered. A range of epistemologies exists, and various ways of knowing were explored here, including objectivism, subjectivism, and constructionism.

Historically, objectivism has informed much of health research. This epistemological stance began in the Enlightenment and proposes an accurate knowledge of the world, where we are assured of a truth that is not ambiguous or speculative (Crotty, 1998). Objectivism may be "positivist" or "post-positivist" but these branches of objectivism put forward that truth and meaning "reside in their objects (i.e. the phenomenon of interest), independent of consciousness" (Crotty, 1998). To consider subjectivism is to consider that meaning is imposed on the object by the subject (i.e. the individual). There is no interplay between subject and object since the object does not contribute to the generation of meaning (Crotty, 1998). Within subjectivism, meaning is made of a variety of starting points such as dreams, primordial archetypes or belief systems (Crotty, 1998) but knowledge does not come from the object, or phenomenon of interest. Third, constructionism, as a way of knowing, contends that meaning is constructed rather than discovered, and meaning is neither objective nor subjective (Crotty, 1998). Humans construct meaning by interpreting the interactions we have as we engage with the world. In this understanding of knowledge, different people construct meaning in different ways, even as they relate to the same phenomenon (Crotty, 1998). When we study how humans construct their views and actions, or when we study what humans consider to be real in a particular time and place, this research is constructionist (Charmaz, 2014).

For this present study, constructionism was the epistemological stance used to consider knowledge about patient decision making in breast cancer. This way of knowing allows for the individual to describe their experience of engaging with the world and the phenomenon of interest, while the researcher considers the perception of the individual as she constructs meaning in her context. As an epistemology, constructionism lends itself well to research seeking an understanding of the experience of individuals or groups in a specific context.

Theoretical Perspective

Theoretical perspective is the way in which researchers may view social life within the human world (Crotty, 1998). These perspectives ground the logic of the study (Crotty, 1998) as well as the development of the methodology and method, such as the criteria for participant inclusion and exclusion, question guides and methods of data collection and analysis. Thus the context of the research study needs to be congruent with the theoretical perspective. When detailing theoretical perspective, we also acknowledge the assumptions that researchers bring to the research design process. While research assumptions have been detailed in chapter one, the researcher also makes known his or her assumptions through the use of, and in the explaining of, chosen theoretical perspectives (Crotty, 1998). In order to understand the complex experiences of women across an age range, this study was guided by two perspectives – a lifespan perspective and a gender perspective. Where lifespan is an issue to be explored in cancer, gender is a lens through which development is viewed.

Gender Perspective

Although gender and sex are interrelated (Canadian Institutes of Health Research, 2012), “gender” is viewed as a social concept and “sex” is seen as the biological characteristics that distinguish females from males (Canadian Institutes of Health Research, 2012). Much variation between females and males can be attributed to biology, but there is a growing understanding that variation can also be associated with “gender”, particularly the social conditions (Bird & Rieker, 2008) that individuals encounter.

The investigation of these social conditions, as related to gender, was attended to in the design of the study. In order to investigate how gender may influence the choices of women with cancer, the complex social conditions of the women were explored, such as women’s actions about their relationships with other persons and institutions. An examination of how these relationships interact with women’s values and preferences was undertaken, in an effort to understand how these values influenced decision making in this context. Components of gender were emphasized throughout the chosen methodology and methods of this study, from the relational approach underlying the methodology of constructive grounded theory (Charmaz, 2006), to the creation of the question guides.

A gender perspective connects with lifespan perspective in this study, since it is the lens in which lifespan development is viewed. While lifespan was a topic of interest, a gender perspective was used in order to bring the women to the centre of the analysis (Charmaz, 2011). This study focused on the lives and concerns of women of all ages, as well as the institutional arrangements that affect them (Charmaz, 2011). This study considered these issues, and placed them at the centre of decision making for women across an age range, in the context of a new cancer diagnosis. It was through the exploration of the social conditions of women, that the experience of decision making was clarified in the context of cancer; and a greater understanding could be reached, regarding the role of society and our institutions, in the constraint and permission of decision making for women with this disease.

Operationally, a gender perspective was emphasized in the interview guide development. Women were asked to describe their relationships with others and the institutions that they encountered while facing cancer decisions. A gender perspective was not relied on for data analysis, but the researchers remained open to explore categories of analysis which contained gender concepts.

Lifespan Perspective

A lifespan developmental perspective was used to explore decision making across a range of ages of women with breast cancer. Although there are a great many types of developmental perspectives in which to guide research (Lerner & Overton, 2010), this study seeks to understand how individuals respond to decision making situations in the context of illness, and how this changed across the lifespan. This study takes a relational position in terms of development, that is, development is driven by a holistic system of internal and external forces that are resources for development in an individual, and an individual's actions are integral in driving his or her own development (Lerner & Overton, 2010).

Also, change is a defining feature of development and change occurs across time for individuals, families, cultures, societies and ecologies (Lerner & Overton, 2010). Developmental changes include changes in the meanings women make of their diagnoses, how they respond to decision making situations due to their relationships, and what women value in a time of illness. Although a woman's age may be a starting point from which to describe developmental changes in decision making, "aging" is different from "development", since age is a descriptive term rather than an explanation of what is occurring (Lerner & Overton, 2010). As a result, is not the specific ages of women that were a focus of the final analysis, it was any changes they described when considering the similarities and differences between women of various age groupings.

Operationally, a lifespan perspective was emphasized most specifically in the interview guide development and in the data analysis. Through the interview guide, women were encouraged to describe the contexts of their lives, and the experience of decision making, at the age and stage in which they are situated. In data analysis, lifespan was considered by grouping women in younger, middle-aged and older age groups for one level of analysis.

Methodology

The research methodology is a strategy that directly leads to the choice of research methods (Crotty, 1998), and links those methods to the research purpose or questions. In the case of this study, the purpose was to explore a phenomenon that is process oriented;

grounded theory was selected as the research methodology because it lends itself to illuminating human processes. This methodology lends itself to examining actions and processes of individuals and groups, particularly the basic psychological and social processes (Charmaz, 2006, 2014; John W. Creswell, 2007) at work within a particular experience, such as decision making in illness. A constructivist grounded theory methodology successfully provided insight about how, in the context of new diagnoses, women interpreted their social world and how they made sense of these experiences across the lifespan.

While grounded theory can be described as both a methodology and a method (Charmaz, 2014), as a methodology it examines the standpoint of the participant, including their historical locations and social circumstances (Charmaz, 2014). While grounded theory continues to develop, this study used constructivist grounded theory – fashioned after the description of this methodology by Kathy Charmaz (2006, 2014). This is an interpretive methodology, emphasizing the processes of interaction among humans, multiple social realities, and it aims toward interpretive understanding of the meanings of the participants (Charmaz, 2014; John W. Creswell, 2007).

As an interpretive approach, this methodology acknowledges that data is collected and analyzed through the interpretive lens of the researcher (Charmaz, 2014; John W. Creswell, 2007). Researcher reflexivity is required, since the researcher must be aware of the extent that the researcher and the research process influence the data and analysis (Charmaz, 2014). Thus, although an interpretive methodology, it is the participant voice that drives the analysis; systematic methods of data collection and analysis ensure this, as described in the next section, by preventing researchers from putting their own motives, fears, unresolved personal issues in to the data collection (John W. Creswell, 2007).

Method

Methods are the activities researchers engage in to answer the research questions (Crotty, 1998). In other words, methods are tools for data collection and analysis, which include specific techniques used and procedures followed. There are a diverse range of methods available to the qualitative researcher, both for data collection and analysis. When choosing methods for research, these methods must align with the methodology, which also must be congruent with the theoretical perspective and the epistemological stance of the researcher.

The primary researcher’s Master thesis study showed that it was likely that a descriptive theory, or model, could be generated about the experience through the utilization of a qualitative methods. Since this study calls for real-life, contextual understandings that will contribute to theory development (Creswell, Klassen, Plano Clark, & Clegg Smith, 2010), qualitative data collection and analysis occurred utilizing the tenets of constructivist grounded theory. In this way, a theory or model may be generated through the examination of the context and meaning of the experience. This methodology involves a flexible system of guidelines (Charmaz, 2006), that allow researchers to synthesize data, analyze contradictions, interpret data and show relationships within a process (Charmaz, 2006); theory is generated by gathering and constantly comparing empirical data (Clarke, 2007). Thus, fundamental to grounded theory includes the simultaneity of data collection and analysis (Charmaz, 2006, 2014; Glaser & Strauss, 1967). Methods chosen for data collection and analysis included: participant interviews, field notes, a demographic questionnaire, constant comparison, coding techniques, and memo-writing.

Recruitment and Sampling

The study was conducted in Manitoba, Canada. Participants were women diagnosed with breast cancer of any stage or subtype, but without a recurrence. Experiences of women soon after diagnosis were sought, yet experiences making a variety of treatment decisions were valued. Therefore, women were invited to participate if they were either: 1) within one year of diagnosis, whether they had received treatment or not, or 2) if they were within one year of completing treatment. This allowed for women to describe experiences making decisions about treatments that more commonly occur several months after diagnosis, such as hormone therapy treatment.

Identification of participants. Several strategies were in place to recruit participants to this study. Recruitment was conducted by clinicians within CancerCare Manitoba, The Breast Health Centre, and Southern Health-Santé Sud Regional Health Authority. All recruiters received a letter explaining the study and their responsibilities as a recruiter, as well as a recruitment script (Appendix A, B). These individuals were asked to identify potential participants and provide these individuals with a letter of invitation (Appendix C). Posters and postcards (Appendix D, E) were placed where appropriate. Posters and postcards were removed from sites and clinics following initial sampling, so as to not recruit women that do not add to development of the emerging theory or model.

Initial sampling. Initial sampling used a theoretical basis as a starting point and this study looked to the lifespan perspective to begin the sampling procedure. Since the age of the women at diagnosis may affect her cancer experience (Stava et al., 2006), women were initially recruited to represent a continuum of ages. Prior research has compared various experiences in cancer among women under and over age 50, and yet there are many changes which women experience during the adult lifespan which may need further delineation. As a result, three age groupings were created for the purposes of initial sampling: younger women (under age 45 years), middle-aged women (aged 45-64 years), and older women (aged 65 and older). The theoretical groups used in this present study are based on research conducted by Stava et al. (2006), which compared the health profiles of breast cancer survivors by grouping them similarly; however, the lowered limit of the older age group was raised from 55 years to 65 years at the suggestion of healthcare providers, based on their clinical experiences.

The hope was to recruit three to five women to represent each group for the initial sample. However, the balance of the age groups in the initial sample became uneven, due to difficulties in recruiting older women. Younger women responded quickly to study invitations, with an initial recruitment of five younger participants. At this point, recruiters were asked to invite women over the age of 45 years, resulting in six middle aged women being recruited. Subsequently, recruiters were asked to exclusively invite women over the age of 64 years, resulting in two older women being entered into the study to complete the initial sample with a total of 13 women.

Theoretical sampling and saturation. The constant comparison of data from the initial sample showed various criteria in the context of a woman’s life which needed further exploration. Following the initial recruitment, and as preliminary categories were found through data analysis (Charmaz, 2006, 2014), theoretical sampling dictated the remaining recruitment with an aim to balance the age groups as best as possible. As well, an effort was put forward to recruit women from rural areas, a demographic gap identified following the initial sample. As a result, another 9 women were recruited (2 younger, 3 middle aged, 4 older; 3 of these women from rural areas). After 22 participants were recruited, it was evident that no new information was emanating from the collected data; the experiences of the participants were categorized within the established coding scheme (see data analysis section below), and no more themes were emerging from the data. As such, it was decided that, for the purpose of this study, theoretical saturation was reached.

The Participants

The sample was comprised of 22 women with a breast cancer diagnosis who received outpatient care. (see Table 1). This number satisfies the requirements of grounded theory based on sample estimates (Charmaz, 2014; John W. Creswell, 2007). The average age of the women was 54.59 years (range of 32 to 80 years). Since lifespan was a focus for this study, data was analyzed at the individual level and then grouped by participant age: under age 45 years (N=7), age 45 to 64 years (N=9), and age 65 years or older (N=6).

Data Collection

Gathering highly descriptive data enables the theoretical outcome to be detailed and full (Charmaz, 2006). Data was collected at two points in time, and via three methods: a demographic questionnaire, semi-structured interviews, and field notes. The research questions in this study required the researcher to go into the contexts and experiences of the participants as best as possible. As a result, data collection methods were used which were grounded in the human experience so as to draw out accurate and comprehensive explanations and interpretations of this experience.

Among this sample, the women participated in a total of 29 interviews (22 initial interviews; 7 follow-up interviews). A further 4 women provided follow-up information via email. Over the course of 29 interviews, the average length of interview time was 67 minutes (range of 36 to 131 minutes). Each potential participant was met at a time and place convenient to both the participant and the interviewer. Written consent was obtained prior to any data collection (Appendix F). Participants completed a demographic questionnaire (Appendix G) at the initial interview and were invited to participate in a follow-up interview, as needed, after the initial sampling was complete. All interviews were digitally recorded and transcribed to ensure accuracy, and specific names of people and places were deleted from the transcripts. Recordings were destroyed after the transcription was completed. Field notes were taken following each interview describing the setting of the interview, and providing a record of the participants' non-verbal expressions as well as the interviewer's thoughts. These notes were incorporated into memos and attached to the interview transcripts.

The role of the interviewer is to bring forward the expertise of the informant, and to listen, observe, and encourage a full response (Charmaz, 2006). As a result, the initial interviews followed a guide (Appendix H), comprised of open-ended questions, which explored each woman's decision making experience. The question guide was a reflection of the literature review and the pilot study, and a revision of the guide was not deemed necessary during the course of the study.

The initial interviews focused on the *context* of the women's lives (before diagnosis, at diagnosis, and since diagnosis), descriptions and interpretations of *specific decisions* chosen by participants (including what matters most, what influenced their decision, and where they felt unable to decide), the participant's *age and/or stage of life* (what it is like to be diagnosed at that age and what they think others should know about women that age experiencing cancer). A conversational approach was adopted, and provided participants an opportunity to reflect on their experience, to tell stories of their own choosing, to share significant experiences, and to receive affirmation and gain a sense of understanding and being heard. When women took part in a follow-up interview, these interviews followed a specific interview guide (Appendix I) which contains open-ended questions to discuss updates, changes or new thoughts that have arisen for the participant since the initial interview.

Data Analysis

Demographics. Socio-demographic information was translated into an electronic spreadsheet and this data was analyzed using basic descriptive statistics.

Interviews and field notes. Field notes were attached to audio transcriptions and saved as pdf files. These files were then uploaded into data analysis software (ATLAS.ti). Each transcript was read and re-read during this process, in order to clean the data of any identifying information and to understand the whole story of the individual. Constant comparisons were made throughout the analytical process. In this study, comparisons were made within an individual transcript (individual level), between interviews (whole sample), within groups of transcripts (group level), and as new data was collected and added to the study. The analysis process was comprised of three cycles of coding (Table 1). Codes and categories developed were reviewed and validated by the primary researcher’s advisor (RW).

Table 1

Coding Cycles for Data Analysis

Coding cycle	Coding type	Description
First cycle		
	Initial	Incident-by-incident coding used to break down the data into discrete parts (Charmaz, 2006)
	Process	Using gerunds ("-ing" words), preserving the actions of participants (Charmaz, 2006)
	In vivo	Verbatim coding, preserving the view and voice of the participants (Saldana, 2012)
	Values	Reflecting participant values, attitudes, and beliefs (Saldana, 2012)
Second cycle		
	Focused	Developing categories from significant or frequent codes; conceptual representations of the data as a whole (Charmaz, 2006)
	Axial	Relating conceptual categories to each other (Saldana, 2012)
	Theoretical	Integrating conceptual categories into a coherent form (Charmaz, 2006)
Third cycle		
	Versus	Identifying binary experiences between participants (Saldana, 2012)
	Pattern	Identifying a configuration of codes (Saldana, 2012)

First cycle coding. The first cycle of coding methods was decided a priori, however the codes came from the data itself. This cycle of coding took place at the individual level, rather than whole sample or group level. This cycle included initial coding, process coding, In Vivo coding, and values coding (Saldana, 2012). The first cycle of coding generated 833 separate codes in the initial 13 participant interviews.

Second cycle coding. Second cycle of coding included methods that were "advanced ways of reorganizing and reanalyzing data" (Saldana, 2012, p.207). Constant comparisons were used when examining codes, and codes were retained that were indicative of the experience of decision making in the initial 13 participant interviews. Focused coding and theoretical coding were decided a priori, due to their affinity with constructivist grounded theory, while axial coding was undertaken in an effort to understand how categories relate to each other. This coding took place at the individual level. Through the process, 12 conceptual categories were identified with several sub-categories (presented in chapter four).

Next, the 13 original participant interviews were recoded, utilizing theoretical coding methods, in order to continue to develop a theoretical understanding of the experience of decision making for women in this context. Any new participant interviews were also coded with the 12 categories (and sub-categories), keeping an openness to the development of new codes and categories. The last two to three interviews from each age group did not produce any new codes or categories. It was during the process of theoretical coding that the analysis progressed to the level of considering the sample as a whole.

Third cycle coding. The conceptual categories for the experience of decision making had been identified, and the decision was made to recode the transcripts for a third cycle of coding; this time, scanning the transcripts and looking only at the incidents where versus coding and pattern coding would be instructive to the analysis. Again, this cycle of coding was at the level of the whole sample and contributed to a growing theoretical understanding of the experience of decision making in this context.

Group level analysis. After analyzing the individual participants and the sample as a whole, the age groups were analyzed using the “query tool” in the data analysis software. To do so, the participant interview data were clustered into demographic groups (younger, middle age, older), then Boolean operators (e.g. “AND,” “OR”) were used to explore data categories between groups. In this way, an output of each category data was clustered by demographic group and cross examined for each conceptual category. For example, the query tool allowed a request for “young” AND “values” data. As a result, all the quotations belonging to younger women AND categorized as values data was provided. The group level of analysis allowed for a close look at the similarities and differences between each age group.

Memo-writing. Beyond coding, memo-writing was used; these are informal, spontaneous writings (Charmaz, 2006) which allow for the integration of ideas and making sense of the data. Memos articulate comparisons, develop subcategories, and link categories. By explicating ideas and processes found in the data, memos raise codes to an abstract level (such as conceptual categories), and to become elements of the emerging theory (Charmaz, 2006). *Early memos* assisted in articulating what the experiences a participant conveyed, as well as connections within or between interviews; *advanced memos* allowed for comparisons between categories and subcategories, defined categories and articulate rules for the inclusion of data in a category. Once the data was deemed theoretically saturated, the memos were sorted, compared and integrated to move further toward an organized and logical analysis (Charmaz, 2006). At this point the constant comparison took on a growing abstraction, and the final result was the development of an analytic interpretation of the participants' experience (Charmaz, 2006).

Evaluation of the Research and Enhancing Trustworthiness

The end product of constructivist grounded theory has criteria for evaluation. Charmaz (2006, 2014) explains that grounded theory studies must be:

1. Credible: The study must achieve familiarity with the topic, have sufficient data, the analysis made via systematic comparisons, it must cover a range of empirical observations, have strong logical links, and provide sufficient evidence.
2. Original: The study must have categories that offer new insights, analysis must provide a new conceptual understanding, it must have social and theoretical significance, and challenge/extend/refine current ideas/concepts/practices.
3. Resonant: The study categories must portray the fullness of the experience, liminal/unstable meanings are revealed, links are made between institutions and individual lives, and the theory makes sense to people who share this experience and offers insights about their lives and their worlds.
4. Useful: The analysis must offer interpretations that can be used in the everyday world, categories may suggest generic processes which are examined for tacit implications, the analysis should spark further research in substantive areas, and the overall work will contribute to knowledge and making a better world.

These criteria provided goals for the final analysis in constructivist grounded theory research and, in turn, informed the study design so these goals could be met. However, in the end, the audiences for this study (e.g. patients, family members, clinicians, policy makers, researchers) will judge the credibility, originality, resonance, and usefulness of the final product. The criteria have been set, but the evaluation of these findings will take place over time by these audiences.

In the meantime, the trustworthiness of these findings can be assessed. In order to realize trustworthiness, the researchers undertook other strategies to insure that these findings are reliable and valid (Golafshani, 2003). First, the primary researcher (HCE) attended to procedures for informed consent (Lincoln & Guba, 2013), taking care to empower participants to disclose their full experience in the course of data collection. Second, the researcher attended to any discrepancies between demographic questionnaire content and any descriptions by the participant. If discrepancies occurred, the researcher followed-up with the participant in order to gain a full understanding. Third, an audit trail (Bowen, 2009) was used to record the data collection, as well as the decisions of the researcher during the research process, and was shared with the primary researcher's advisor (RW) who validated the process. The audit trail included:

1. The initial literature review, as well as study protocol and instrument development, overseen by the advisor (RW) and two committee members.
2. Ethics board approval of the study and oversight.
3. Participant selection, guided by ten study recruiters with extensive clinical knowledge of the experience of women with breast cancer.

4. Data was shared with advisor, who evaluated the quality of the data (raw data, code and category lists, notes on the process, diagrams of early findings, memos on the data, and later data analysis notes and diagrams).
5. Re-examination of data was undertaken to better understand negative cases, in order to see if negative cases disconfirmed findings.
6. Data analysis was conducted by two researchers (HCE and RW), to insure that the findings came from the data rather than the worldview of one researcher (Bowen, 2009); this occurred though regular contact between the researchers, where data was shared and discussed.
7. A second literature review was conducted in order to understand emerging categories of analysis.
8. Thick descriptions of the findings (including participant quotations) are included in this report in an effort to provide adequate information, so that other researchers can transfer these findings to their own (Bowen, 2009).

This transparent process supports the credibility, dependability, confirmability, and transferability of findings (Denzin & Lincoln, 1994), further increasing the confidence that these findings contain truth, and that the concepts included are sound.

Ethical Considerations

Ethical approval was obtained from the University of Manitoba's Research Ethics Board (ENREB) and the impact committees at CancerCare Manitoba (CCMB), the Winnipeg Regional Health Authority's (WRHA) Breast Health Centre (BHC), and Southern Health-Santé Sud. Ethical considerations are of primary concern through the development of this study. Particular attention was paid to informed consent, confidentiality, and risk. All participants in this study were provided information about the study and opportunities to ask further questions before consenting to participate. Written consent was obtained prior to data collection. All participants were assigned a unique identifier for confidentiality purposes. Where participants revealed other identifying descriptions in interviews (persons or places), these were removed from the data. The Principal Investigator (HCE) had the only record that linked identifiers with participants; this document was kept secure and separate from other study documents, and destroyed following data collection.

This study had minimal potential harm, however recalling the time of diagnosis and early decision making in cancer had the potential to involve emotional distress for participants. Care was taken to respect the feelings of individuals, by letting participants tell their stories in an open-ended manner without intrusive questions. All participants were provided the contact information of Patient and Family Support Services at CCMB, as well as information about resources that can be obtained at no cost through that department. There were potential benefits for study participants, including the opportunity for participants to share their stories and contribute their personal experiences to the development of a theory which will help explain their situations to others.

Summary

A constructionist epistemology, as well as gender and lifespan theoretical perspectives, guided the study design. A constructivist grounded theory methodology was utilized to meet the purposes of this study so that we may better understand the experience of decision making for women with invasive breast cancer across the lifespan. Methods were chosen as consistent with this methodology, including participant interviews, field notes, a demographic questionnaire, constant comparison, coding techniques, and memo-writing.

CHAPTER 4: INTRODUCTION TO THE FINDINGS

Data analysis generated a model to describe *ways of learning in breast cancer*. Where women with breast cancer may encounter the problem of not understanding, yet needing to make treatment decisions, this model explains the process of learning about cancer and its treatment when women are facing treatment decisions. The findings also include a description of the barriers to information support, as experienced by women with breast cancer. This introductory chapter introduces the participants of the study, provides descriptions of the categories of analysis that came from the data, the subsequent findings chapters in this thesis, to research perspectives, and addresses the three research objectives.

Participants

Of the 22 study participants, 7 women were “younger”, 9 women were “middle aged,” and 6 women were “older” (Table 2). At the time of the first interview, the average time since diagnosis was 9.45 months (ranging from 1 to 31 months). Participants described their cancer diagnoses in their own words, including their understanding of the stage of the cancer. Women reported their diagnoses as Stage 1 (N=7), Stage 2 (N=8), Stage 3, (N=6), and Stage 4 (N=1).

Table 2

Participant Ages, Stage of Cancer and Decisions Made

	Total	Younger	Middle age	Older
No. of women	22	7	9	6
Average age* (range)	54.6 (32-80)	39.3 (32-43)	54.8 (48-64)	72.2 (66-80)
Diagnosis stage**				
Stage 1	7	2	4	1
Stage 2	8	1	3	4
Stage 3	6	4	1	1
Stage 4	1	0	1	0
Decisions made at time of interviews (%):				
Lumpectomy	11 (50)	2 (28.6)	5 (55.5)	4 (66.7)
Mastectomy	11 (50)	5 (71.4)	3 (33.3)	3 (50)
Reconstruction	7 (63.6)	3 (60)	2 (66.6)	2 (66.6)
No reconstruction	4 (36.5)	2 (40)	1 (33.3)	1 (33.3)
Chemotherapy	16 (72.7)	5 (71.4)	8 (88.9)	3 (50)
Radiation therapy	15 (68)	6 (85.7)	7 (77.8)	2 (33.3)
Hormone therapy	15 (68)	5 (71.4)	8 (88.8)	2 (33.3)

Notes:
*in years
**self-reported
Younger: Age ≤ 44 years
Middle age: Ages 45 – 64 years
Older: Ages > 65 years

Since this study concerns treatment decision making, a summary of treatment decisions is included (Table 2). At the time of data collection, it was observed that participants had completed the following surgeries: lumpectomy (N=10), mastectomy (N=11), breast reconstruction (N=7), no breast reconstruction (N=4). One participant was not offered surgery due to her type and stage of cancer. Participants also described other treatment decisions: chemotherapy (N=16 [3 not offered; 1 underwent genomic testing and did not take chemotherapy as a result; 1 started chemotherapy but stopped early; 1 unknown]), radiation therapy (N=15 [1 declined; 5 not offered; 1 unknown]), hormone therapy (N=12 [2 not offered; 3 started hormone therapy but stopped early; 5 unknown]), genomic testing (N=2 [2 wanted but did not get it done; 1 was considering but unknown if test was done, 17 unknown]), fertility preservation (3 of 7 younger women considered these services but did not have access to fertility preservation prior to treatment).

Other socio-demographic information was collected as well, identifying most women to be from urban centers (N=19), with 3 from rural areas; most women were married and/or living with a partner (N=14), however other women were never married (N=2), divorced or separated (N=4), or widowed (N=2); most women described caregiving activities including caring for dependent children (N=4), caring for children over the age of 18 years but still living at home (N=5), caring for non-dependent children (N=9), providing intensive caregiving for a spouse or aging parent (N=3); many women referred to themselves as very active or somewhat active in their religion (N=12), while other women stated they were not very active (N=2), not active (N=4), or preferred not to say (N=3); four women did not indicate their ethnicity or cultural group, while other women indicated that they identified themselves to be of European (N=14), Aboriginal (N=2), East Indian (N=1) and Caribbean (N=1) decent; all women spoke English, yet the primary language of four women was not English.; most women completed college, undergraduate or graduate programs (N=16), others completed high school (N=4), or did not have high school education (N=2); many women were on leave from paid employment (N=9) or retired (N=7), other women were in paid employment at the time of their interviews (N=4) or doing unpaid work at home (N=2); all women received care as out-patients and 18 were receiving treatment at the time of the initial interview (surgery [N=2], chemotherapy [N=4], radiation therapy [N=1], hormone therapy [N=11]); interviews were conducted in the homes of the participants (N=15) or in a private room at the local cancer care centre (N=7).

Generating the Categories of Analysis

The creation of this model was an interpretive process (Charmaz, 2014), a process which interprets the meanings and actions of the participants. Categories of analysis were generated through analysis methods listed in chapter three, and were influenced by gender and lifespan perspectives, as well as the perspective of the primary author. Twelve categories of findings were used to create this model, each are provided and defined in Table 3.

Table 3

Categories of Analysis Regarding the Experience of Decision Making

Category	Description
Attitude in decision making	Women’s actions displaying their attitudes toward decision making
Diagnosis	The experience of diagnosis; understanding of cancer and treatment at diagnosis; the meanings made of diagnosis
Getting an understanding	Women’s efforts to understand cancer and its treatment: the experience, information sought, the source of information ways of being advised, determining who has the responsibility for decision making
Goals of care	Determining the priorities and wishes of women
Lifespan issues	How women’s ages and activities may or may not influence decision making
Needs	Support needed during decision making
Other considerations	Issues that overlap or intertwine with decision making: other activities and priorities, beliefs about decision making, intuition and personal hypotheses, meaning of treatments, prior history and life experience
Presenting options	The experience of patient education
The process	Procedural explanations of how a decision was made
Triggers	Events or feelings which brought about a specific treatment decision
Values	What was important to women in general, not specific to the treatment decision making context
What helps	Being supported in decision making

Perspectives in Data Analysis

A lifespan perspective. In data analysis, the lifespan perspective provided an opportunity to group women by age and consider the needs and activities of women by age and stage of life. More similarities than differences were found between age groups in the categories of analysis. Where differences occurred, these are described in chapters five and six.

A gender perspective. A gender perspective guided the study design, more than the data analysis. However, because this perspective influenced the study design, it provided the opportunity for the researchers to reflect on the contexts of decision making and how these may permit and/or constrain women's decision making experiences in breast cancer. This perspective encouraged the researchers to consider the influence of society and institutions on the experience of decision making after a breast cancer diagnosis.

The researcher's perspective. In an interpretive study, the researcher's perspectives intermingle with the data, including data analysis. This way of co-constructing the findings with the participants is consistent with this interpretive methodology (Charmaz, 2014). Researcher reflexivity was attended to as categories of analysis were determined. In particular, the primary author (HCE) found that specific personal experiences were influential in the research process. First, data analysis was interpreted through the primary author's lens as an educator. Having a background as an school teacher allowed the researcher to closely consider how patients attended to, and understood, cancer information. For example, the category "getting an understanding" (Table 3) emanated from data describing the efforts involved in learning new information.

As a teacher, the author was familiar with the effort involved in learning for students in formal learning contexts. While the context of experiencing breast cancer is very different, the author's familiarity with learning caused her to recognize learning processes as women described them in this setting. This specific category was prominent in the data and a category was named from the words of a 40 year old participant. She spoke about meeting with a friend of the family to hear about chemotherapy when she said, "she met with me for awhile to get an understanding of what the chemo might be like (Participant 3)." Although the primary author interpreted the data as an educator, the voices of the participants remained at the forefront of the analysis.

Second, although never diagnosed with cancer, the primary author has had personal experiences with health decision making and, because of this life experience, has an in-depth knowledge of treatment decision making. As a result, the primary author reflected on her own perceptions and existing knowledge throughout the research process, thus allowing her experience to interact with the data. At the same time, the author took steps so that her perspective was not privileged over the participants' multiple perspectives; activities, such as memo-writing about the author's own beliefs and values in treatment decision making, and reviewing data and analysis with the author's advisor aided in bringing out the participant's experiences. The primary author paid attention to draw out unexpected responses from the participants, and was cautious not to repress aspects of the data that did not resonate with her personal experience. Further, participant rapport was built by showing women respect and understanding (Charmaz, 2006) and never via conveying shared experiences in health decision making; in this way, great care was taken to protect the participants from the potential influence of decisions made by the primary author in a similar, yet different, time, place and context.

Study Purpose and Research Questions

The purpose of this study was to develop a theoretical understanding of the experience of decision making in breast cancer across the lifespan. The research purpose was met in two parts. First, the purpose was met through the development of a theoretical model describing the *ways of learning in breast cancer*; a model incorporating women's descriptions of their beliefs, values and actions that led to ways of learning. This model is substantive in nature, and moves research closer toward theory development about learning in the context of illness. Second, the purpose was met through the description of the barriers experienced by women when needing information support in breast cancer. Since these barriers describe patient needs regarding support in eliciting health information, these findings have the potential to contribute to future theory about how patients learn, as well as the process of patient decision making in cancer. Apart from the study purpose, specific research questions were addressed as the study was conducted; each question is detailed below and includes examples of data analysis coding procedures.

What Meanings do Women Assign to Decisions?

During data collection and analysis, close attention was paid to descriptions of the meanings women made of cancer, as well as meanings assigned to specific decisions. Women explained that these meanings influenced how they coped with their illnesses, but they also explained how meanings influenced treatment decision making. Many meanings were described. Multiple meanings were associated with cancer, particularly the diagnosis event, while other meanings were associated with treatments and treatment decisions. Initial codes are described below.

First, women assigned meanings to the experience of being diagnosed with breast cancer. Diagnosis meant a range of things to women, yet most women assigned diagnosis a meaning that arose from the shock and fear experienced. Many of these meanings were a response to the threat of cancer. For example, initial coding procedures showed that a cancer diagnosis meant "facing death," "another battle to fight," "the fight's on," or "being in crisis mode." For example, a 35 year old woman said, "It's (receiving a diagnosis is) kind of being asked to face death in a very concrete way" (participant 1). Another woman, aged 55 years, explained, "people wonder what it would be like it someone told them they were gonna die, for example. So I actually experienced that now" (participant 7). Another woman, aged 58 years, described her first thought at diagnosis. She said, "well, here we go, the fight's on" (participant 9).

Other meanings addressed the immediate shift in women's perceptions of themselves and their worlds at diagnosis. In these cases, a cancer diagnosis meant "loss of control," "being vulnerable," "loss of invincibility," "loss of innocence," "being looked at differently now," or "to be disconnected from the body." A 71 year old woman said, "I now feel more vulnerable…it really bring home that this really can happen… that sense of invincibility is not there (any longer)" (participant 12). Another woman, aged 55 years, explained that she felt very detached from herself and those around her during her cancer experience. She said, "you completely remove yourself… to get through the storm (of treatment), you disconnect from your body in a lot of ways" (participant 7).

Cancer treatment decisions had meanings for women as well. The act of making a treatment decision meant not having a choice for several women. For example, a 55 year old woman explained, "I feel like I got forced, I feel like I got hit over the head" (participant 7). Regarding treatment in general, women assigned meanings that had both "positive" and "negative" aspects. Concerning negative meanings, to face treatment meant "to become feeble or frail," "to lose fertility/strength/ability/appearance/time," "toxicity," "a halt in things (normal life)," "taking a year away from life," and "to need special care." For example, a 35 year old woman said, "(treatment is) to not be able to open jars, to kind of be feeble" (participant 1). An older woman, aged 71 years, explained that she would love to be traveling, but she needed to make treatment decisions that meant "a little halt in things right now" (participant 12).

Yet many meanings were positive and seemed to help women make a treatment decision, even when they were afraid of the effects of treatment. Concerning positive meanings, to face treatment meant "to face cancer," "help reach the goal," "to help myself," "to restart and rebuild," "asking for a new life," "a second chance," and "making me stronger." Some women, like this 40 year old, said that she anticipated that "it will be like a new life" after cancer. She used positive meanings to help accept the treatment decisions she faced. She said, "my attitude towards that (decision), it's basically the only thing I have control over – is how I think, feel about things" (participant 3). Another woman, age 58 said, "the rest of my life is really gonna be kind of focused on just enjoying my life, and appreciating that I got a second chance" (participant 9).

Women shared the meanings they associated with specific treatment decisions, particularly chemotherapy and surgery options. For some women, chemotherapy meant "the cancer has spread (even if it has not)," "bad news," "a year of life taken," "killing the cancer cells," and "stopping recurrence." A 58 year old woman said," (chemotherapy) just kills everything in you" (participant 9). Women reflected on surgery, but most of these meanings described were assigned to breast reconstruction after mastectomy. Reconstruction meant a range of things to different women. For some women, reconstruction meant “invasive, extra surgery,” “room for more error,” “longer recovery,” “removing core body parts,” and “non-essential.” While for other women it meant the “ability to not be breast-less.” One woman provided a meaning for radiation therapy, “being tied down;” here this refers to the need to be close to the radiation therapy centre every day.

These initial codes were incorporated into second cycle codes (e.g. “meaning of diagnosis,” “meaning of radiation,” “meaning of reconstruction”) and these, in turn, were incorporated into later categories (e.g. “diagnosis,” “triggers,” “other considerations,” and “getting an understanding”). In this way, the meanings that women assigned to the cancer experience, including the meanings assigned to decisions, were incorporated into the main findings.

“Ways of learning” was a main finding (see chapter five), that emanated from the meanings women assigned to treatment decision making. Women strove to get an understanding of their diagnosis and the treatment options available to them, all the while being influenced by the meanings they assigned to cancer and the decisions they faced. Women used various ways of learning as strategies to face the challenges involved in treatment decision making. Also, when women approached decisions with specific meanings in mind, they looked for information to either confirm or oppose the meanings they had originally assigned. It is unknown if women changed the meanings assigned to decisions because of the provision of information or through the ways they learned about cancer and its treatment. However, women did describe seeking information that would either confirm or oppose the meanings they assigned to their diagnoses and/or treatment decisions.

How do Psychosocial Factors Influence the Experience?

Women were asked to describe their experiences of decision making, and close attention was paid to psychosocial factors in the data collection and analysis. The psychosocial factors that influenced women's decision making experience were many and varied; these factors tended to overlap in patients' descriptions, since the psychological, social, emotional, spiritual, quality and life, and functional aspects of the illness were often interrelating in nature.

Codes were created early to capture these factors. For example, in the first cycle of coding, "being afraid," "having faith," and "protecting others" became initial codes. In the second cycle of coding, "facing cancer" was a code that incorporated several psychosocial factors from the first cycle of coding (e.g. "accepting," "being at peace"), and "feeling" was another code which incorporated many aspects of the early codes referencing the psychosocial experience (e.g. "fear," "anger," "embarrassed," "worry"). These second cycle codes depicting the psychosocial experience, were incorporated into later categories (e.g. "diagnosis," "what helps," "needs"). Categories were then used to develop main findings presented in this thesis, including the model of *ways of learning in breast cancer*, as well as the barriers to information support described by women. In these ways, the influencing psychosocial factors were incorporated early in the data collection and analysis, and continued to be influential in the development of the findings.

A key psychosocial factor influencing decision making was the emotional distress women felt at diagnosis as they faced treatment decision making situations. This emotional distress was marked by the shock and fear that came with a diagnosis. For example, a 55 year old woman said about her diagnosis, "at first you're so shocked" (participant 7). These feelings influenced how women learned about cancer and its treatment (see chapter five). Emotional distress was also a barrier to women receiving information support because women struggled to attend to cancer information so soon after diagnosis (see chapter six).

Another key factor was the social aspects of women's lives as they considered treatment choices. In particular, women were influenced by their relationships, and paid close attention to their caregiving responsibilities, regardless of their ages, when choosing treatment. On the whole, women chose treatments they felt offered the best chance they would be healthy in the longer term; their priority was to continue to enjoy their families and take care of their loved ones. One 32 year old woman said:

> "Somebody needs to look after those (children) that we have. That was hard, but for me I didn't even have to think about it. I knew right away (to choose the suggested treatment)… it would be better if those children had a mom than not a mom at all." (Participant 19)

Middle aged and older women considered caregiving as well when making treatment decisions (see chapter five).

Relationships, connections to loved ones in particular, provided a goal for women in treatment and influenced treatment decision making in this way. Interestingly, as important as loved ones were in influencing treatment choices, women did not involve their loved ones in treatment decision making apart from having loved ones accompany them to appointments and to debrief information learned. Even when women learned about treatment decisions by trusting a system of connections, women made decisions on their own, with all other relationships taking on a supportive role. This phenomenon was reflected in the main findings regarding ways of learning (see chapter five).

A third key factor involved the quality of life and functional aspects of the cancer experience that influenced treatment decision making. For example, concerning ways of learning, when women were not feeling well, it influenced how they were able to learn about cancer and its treatment (see chapter five). When feeling tired and ill, they did not have the energy to use a system of connections in order to learn about the next treatment decision they were facing. At these times, women trusted the healthcare system in making the next decision. Conversely, women who experienced poor quality of life after undergoing a treatment, took care to expand their systems of connections to learn more about treatment options, despite feeling ill. In this way, the quality of life experienced by women in breast cancer directly influenced how they learned about cancer and its treatment. Similarly, when women experienced a poor quality of life, it was a barrier to information support (see chapter six) because women had more difficulty accessing information support when feeling ill.

How does Decision Making Change Across the Adult Lifespan?

This question was addressed in data collection by asking women about what others should know about women their age and making decision in breast cancer. This question spurred responses from women, detailing what it was like to be diagnosed at their age and what it was like to navigate treatment decision making as women their age.

In the process of data analysis, age groups were compared for any similarities and differences between younger, middle aged, and older women. Initially, these were coded as “younger,” “middle,” and “older.” These were then incorporated into second cycle codes (e.g. “age”), and a later category (“lifespan issues”). In addition to these coding strategies, decisions were compared between age groups in a third cycle of coding that incorporated “versus” coding (identifying binary experiences) and “pattern” coding (identifying a configuration of codes) (chapter three, Table 1). These coding strategies allowed the authors to go back through the data and identify binary experiences between participants of the same age group, or between age groups; this coding also encouraged the identification of patterns of coding within an age group.

In this way, it was found that women of different ages showed different patterns in decisions faced, as well as their ways of learning about breast cancer (see chapter five). While not statistically significant due to the sample size, it can be noted that younger women faced more decisions than older women, with this sample of younger women facing an average of 1.3 more decisions than their older counterparts. This did not reflect treatments that older women may have refused, the difference between groups represents treatment decisions that were offered by healthcare providers. It is unknown why older women faced fewer decisions; a closer investigation of their records would need to be made, or healthcare providers would need to be interviewed, which was outside the scope of this study.

Second, where women of different ages learned by trusting the healthcare system, younger women shifted to trust a system of connection more often than older women. This general pattern that could be seen in the data, yet there were exceptions; some middle aged and older women in this study became very interested in developing a wider system of connections in order to learn about cancer and its treatment, however these exceptions followed experiences where women were unhappy with their previous treatment(s). This differed from the younger cohort of women who shifted their way of learning to trust a system of connections, even when they had not described being unhappy with their previous treatment experience(s).

The Manuscripts

The subsequent two chapters describe findings of the thesis that have been written in manuscript form. The first manuscript (chapter five) describes the model describing *ways of learning in breast cancer*. This manuscript defines the process of learning, and describes the underlying beliefs, values, and actions of women as they learn about cancer and its treatment. The model is presented, as well as a typology of ways of learning. Also, attention is paid to the similarities and differences between younger and older women with a new breast cancer diagnosis.

The second manuscript (chapter six) describes the barriers to information support for women who are facing treatment decisions in breast cancer. Five barriers are presented: emotional distress, patient-provider communication, provider-provider communication, making it personal, and access to information. These barriers exist at several levels (individual, patient-provider, provider-provider, health organization and system, and external to the organization and system). Similarities and differences between younger and older women are presented as well.

Summary

The findings of the study are derived from the data collected from 22 women of various ages with breast cancer. These findings were generated from a process of data analysis; guiding theoretical perspectives, and the perspective of the researcher, were influential in the process of generating categories of analysis. The study purpose and the specific research questions were described, and answers to these questions were provided. Two manuscripts of the main findings are presented in the subsequent chapters of this thesis. Chapter five presents a model, *the ways of learning in breast cancer*, describing the process of learning in breast cancer. This process is used to address the problem experienced by women, that is, women may not understand cancer and its treatment, yet they need to make treatment decisions. Chapter six presents the barriers women described to information support in this context.

CHAPTER 5: WAYS OF LEARNING IN BREAST CANCER

Abstract

Background: In the context of breast cancer, many newly diagnosed women face treatment choices. Accordingly, many women want to understand basic cancer and treatment information. While research has been done on learning in other settings, none has been undertaken in order to explore the experience of learning about breast cancer and its treatment.

Purpose: To explore the experience of treatment decision making in the context of breast cancer, with specific attention being paid to decisions made in the early cancer experience. This paper discusses findings about the ways in which women with breast cancer learn about cancer and its treatment.

Methods: The tenants of constructivist grounded theory were followed, guided by gender and lifespan perspectives. Semi-structured interviews were conducted with 22 women with invasive breast cancer to explore the context and process of decision making in cancer. The average age of women was 55 years (range of 32-80 years), and the average time since diagnosis was 9.5 months. Data was analyzed on individual, whole group, and age group levels. Participant data was grouped by age: younger women, under 45 years (N=7), middle aged women, aged 45-64 years (N=9), and older women, aged 65 and older (N=6).

Findings: Data collection and analysis produced a model of *ways of learning in breast cancer*, describing the process of learning in this context. The beliefs and values of women provided a foundation which influenced their actions and attitudes of learning about cancer and treatment information. Two ways of learning are presented: 1) learning by trusting the healthcare system, and; 2) learning by trusting a system of connections. Several factors influenced women’s ability to move between different ways of learning, and women of all ages engaged in different ways of learning in breast cancer.

Conclusion: Women took part in learning about their cancer and its treatment by trusting the healthcare system and/or trusting a system of connections. These ways of learning guided women as they worked to make treatment decisions. The underlying beliefs and values of women influenced the process, yet women were able to shift between ways of learning over time in cancer. Increasing the awareness of the ways in which patients learn about cancer and its treatment, and assisting women in expanding their connections with others, may provide needed support for women making treatment decisions in breast cancer.

Background

In breast cancer, patients typically face multiple treatment decisions over a period of time. Many of these decisions hold choices for patients where legitimate options exist, and each option may have different short or long term outcomes (Center for Evaluative Clinical Sciences, 2007; Wennberg, 2010). With the potential for differing outcomes due to treatment options, the ability for patients to make decisions is a crucial component of cancer care (Nelson, Stefanek, Peters, & McCaul, 2005). However, research regarding an understanding of how and why patients make treatment decisions in cancer is limited. In breast cancer, little is known about how and why patients engage with the experience of decision making, including engaging in learning about cancer and its treatment. Yet undertaking this research critical, considering there is of evidence that informed and engaged patients have better health outcomes, contributing to efficiencies in health resource use (Coulter, Parsons, & Askham, 2008).

Learning, knowing and understanding are often used interchangeably (Elisabeth Hayes & Flannery, 2000), yet a distinction is made for the purposes of this paper. "Understanding" refers to general insight and the ability to comprehend; it is "the knowledge and ability to judge a particular situation or subject" ("Understanding," 2015). "Knowing" is more specific; it is a steady, stable state that is deeply intertwined with a person's worldview, as well as a person's histories and social experiences (Elisabeth Hayes & Flannery, 2000). The ways in which people know are "coherent interpretive frameworks" (Belenky, Clinchy, Goldberger, & Tarule, 1997) that give meaning to learning. "Learning" is the processes, often cognitive, of acquiring, revising or maintaining knowledge, skills or values (Cranton, 2006; Elisabeth Hayes & Flannery, 2000). Learning is a lifelong activity (Aspin, Evans, Chapman, & Bagnall, 2012; Groen &

Kawalilak, 2015) of acquiring, maintaining, or revising ideas, facts, and skills. These learnings are woven together into meaningful patterns and give rise to knowing – through learning "we come to know" (Elisabeth Hayes & Flannery, 2000). In this way, new or revised learning can alter a person's knowledge or ways of knowing. Since this study is about processes involved in decision making, particularly the processes involved in the consideration of new information, the term *learning* will be used here.

Adult learning occurs in a social context, yet Merriam & Bierema (2014) identify these contexts can be either formal (organized, sponsored by educational institutions), nonformal (organized, sponsored by organization which have an aim that is not educational) or informal (learning embedded in everyday life). Further, informal learning may include other types of learning, such as incidental learning which happens outside of the conscious awareness of the learner while engaging in another experience (Merriam & Bierema, 2014). Therefore, if learning occurs in the process of decision making in cancer, it is likely informal learning.

In various contexts, including the experience of breast cancer, patients are forced to ask themselves difficult questions which are, at their root, questions about knowledge (Belenky et al., 1997). In breast cancer, women ask questions, perhaps unknowingly, to help clarify their treatment choices. These questions refer to learning in this context and may include: What do I consider to be evidence about treatment? Who do I listen to about this? Generally, adults may learn in diverse ways, reflecting a myriad and mixtures of learning styles, information processing styles, and personality patterns (Gardner, Kornhaber, & Wake, 1996; Goleman, 2012; Kolb, 1983; Longworth, 2003). Much is unknown about this process of learning in cancer, and its influence on treatment decision making. This paper discusses findings specific to women's ways of learning about cancer and treatment information in breast cancer. These findings were derived from a study that explored the experience of decision making for women with breast cancer, with specific attention being paid to the similarities and differences in the experience of younger, middle-aged and older women.

Method

This qualitative study follows the tenets of constructivist grounded theory (Charmaz, 2006, 2014). Whereas this subject has not been widely previously explored, this interpretive methodology (Charmaz, 2014; Watling & Lingard, 2012) lends itself to understanding the human experience of decision-making in a complicated context by enabling the researchers to examine actions and the psychosocial processes of individuals (Charmaz, 2006; Creswell, 2007).

Participants were women diagnosed with breast cancer of any stage or subtype, but without a cancer recurrence. Experiences of women soon after diagnosis were sought, although it was recognized that time was needed for women to encounter the many treatment decisions they would face. As a result, women were invited to participate if they were either: 1) within one year of diagnosis, whether they had received treatment or not, or 2) within one year of completing treatment. Because the study calls for a lifespan perspective, younger (under 45 years), middle aged (45 to 64 years), and older (65 years and older) were recruited. These theoretical groupings were initially based on previous research (Stava, Lopez, & Vassilopoulou-Sellin, 2006), but the lower limit of the older age group was raised from 55 to 65 years at the suggestion of healthcare providers, based on their clinical expertise.

The study sample was comprised of 22 women recruited from ambulatory care settings (Table 1). After 22 participants were recruited, no new information emerged from the collected data and it was decided that theoretical saturation was reached. Among this sample, women participated in a total of 29 interviews (22 initial interviews, 7 follow-up interviews).

Table 1

Participant Ages, Stage of Cancer and Decisions Made

	Total	Younger	Middle age	Older
No. of women	22	7	9	6
Average age[*] (range)	54.6 (32-80)	39.3 (32-43)	54.8 (48-64)	72.2 (66-80)
Diagnosis stage[**]				
Stage 1	7	2	4	1
Stage 2	8	1	3	4
Stage 3	6	4	1	1
Stage 4	1	0	1	0
Decisions made at time of interviews (%):				
Lumpectomy	11 (50)	2 (28.6)	5 (55.5)	4 (66.7)
Mastectomy	11 (50)	5 (71.4)	3 (33.3)	3 (50)
Reconstruction	7 (63.6)	3 (60)	2 (66.6)	2 (66.6)
No reconstruction	4 (36.5)	2 (40)	1 (33.3)	1 (33.3)
Chemotherapy	16 (72.7)	5 (71.4)	8 (88.9)	3 (50)
Radiation therapy	15 (68)	6 (85.7)	7 (77.8)	2 (33.3)
Hormone therapy	15 (68)	5 (71.4)	8 (88.8)	2 (33.3)

Notes:
[*] in years
[**] self-reported
Younger: Age ≤ 44 years
Middle age: Ages 45 – 64 years
Older: Ages > 65 years

The average age of the women was 54.59 years (range of 32 to 80 years). Since lifespan was a focus for this study, data was analyzed at the individual level and then grouped by participant age: under age 45 years (N=7), age 45 to 64 years (N=9), and age 65 years or older (N=6). The average time since diagnosis was 9.45 months (ranging from 1 to 31 months at the first interview). Women reported cancer stage and treatment choices, as included in Table 1. Most women were married or in common-law relationships (N=14), 4 were divorced or separated, 2 women were widowed and 2 never married. Four women did not indicate their ethnicity or cultural group, while other women indicated that they identified themselves to be of European (N=14), Aboriginal (N=2), East Indian (N=1) and Caribbean (N=1) decent. All women spoke English, yet the primary language of four women was not English.

Data was collected by the first author (HCE) at two points in time, and via three methods: field notes, a demographic questionnaire, and semi-structured interviews (Figure 1). Lifespan and gender perspectives guided the development of the interviews, since women were asked about the experiences of being women of their age making decisions in breast cancer. Participants were offered a second interview to provide follow-up information, including providing an update on changes that may have occurred and any new decision making experiences. Over the course of 29 interviews, the average length of interview time was 67 minutes (range of 36 to 131 minutes).

Figure 1

Interview Guide

1. What was life like before you were diagnosed with cancer?
2. What was it like to be diagnosed with cancer?
3. What has happened since you were diagnosed?
4. What is a decision making experience that you would like to tell me about?
5. Can you tell me about any treatment decisions?
6. Was there a decision that you felt you were unable to make, perhaps you felt stuck or unable to act?
7. Earlier you mentioned (decision), can you tell me more about that?
8. Is there an issue that you are currently making a decision about?
9. What do you think people should know about women your age and making decisions after a breast cancer diagnosis?
10. Is there anything else I should know to help me better understand decision making in breast cancer?

Data was analyzed by two authors (HCE and RW). Socio-demographic information was translated into an electronic spreadsheet and was analyzed as basic descriptive statistics. Field notes were attached to corresponding interview transcriptions and were uploaded into data analysis software (ATLAS.ti). Each transcript was read and re-read to understand the experience of the individual. Constant comparisons (Charmaz, 2006) were made within individual interview data, and between interviews across the whole sample. A lifespan perspective was used in the data analysis, therefore care was taken to analyze interview data from each age group. Comparisons were continually made, as new data was collected and added to the study.

Various coding methods were utilized to enhance the depth and breadth of the findings, including initial, process, values, pattern and versus coding (Saldana, 2012). Memos were written throughout the process of data collection and analysis, which allowed for the explication of ideas and processes found in the data and raised codes and categories to an emerging theory (Charmaz, 2014). As analysis developed and the category arose regarding ways of learning about treatment choices, decision incidents were listed for each participant in the order that the participant indicated they occurred. Individual decisions were analyzed to categorize each decision.

Ethical approval was obtained from the University of Manitoba's Research Ethics Board (ENREB) and the impact committees at CancerCare Manitoba, the Winnipeg Regional Health Authority, and Southern Health-Santé Sud. All participants were provided information about the study and opportunities to ask further questions before consenting to participate. Written consent was obtained prior to any data collection. Participants were assigned codes to protect their identities, all identifying information was stored securely and separate from the data.

Findings

The overall findings of this study identified categories of analysis which formed a model to describe women's *ways of learning in breast cancer*. This model (Figure 2) describes the process of learning about cancer and treatment information that occurs in breast cancer treatment decision making, and presents two specific ways that women learn about treatment options. The model shows the cyclical process of learning women used to construct their preferences, as described by these women in the context of a new cancer diagnosis. It is comprised of four main components:

1. ways of learning;
2. beliefs, or the ideas women held to be true about knowledge (Saldana, 2013, p.111);
3. values, or the importance we attribute to self, others, things, or ideas (Saldana, 2013); and

4. actions relating to learning. Attitudes, or the way women thought and felt about themselves, others, things, and ideas (Saldana, 2013), are included in the "actions" component of the model, since women displayed their attitudes towards the decision making experience in their descriptions.

Two ways of learning were found in the analysis. Table 2 details these ways of learning, revealing the specific beliefs and values underlying each way of learning as well, as the actions which indicate ways of learning. The findings describe the model on ways of learning in breast cancer, as well as the two types of learning observed in this sample. The ability for women to move between ways of learning in breast cancer is also described.

Figure 2

Model: Ways of Learning in Breast Cancer

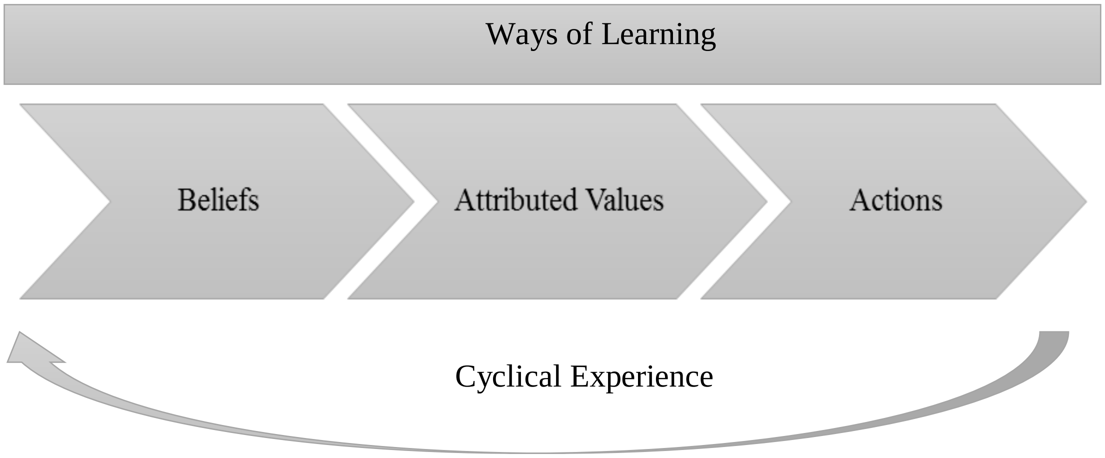

Table 2

A Typology of the Ways of Learning when Making Treatment Decisions in Breast Cancer

Ways of Learning	Belief	Value	Actions
Trusting the healthcare system: "I have faith in the system"	Healthcare system holds authoritative knowledge; the system holds specialized cancer knowledge and is the key to survival; there is goodness in education, training, and the guidelines/protocols accessed through the healthcare system	Professions, institutions and organizations, as well as resources held within institutions and organizations, are highly regarded.	Dyadic connections to receive recommendations from professionals; did not discuss personal priorities and few questions were asked; displayed an attitude of acceptance of recommended treatment
Trusting a system of connections: "I need to know about my cancer"	A range of sources hold authoritative knowledge; there are many ways to learn about surviving cancer; different people and different resources hold different cancer knowledge; different patients have different needs	A personal understanding of cancer and/or the cancer subtype, as well as a personal understanding of specific treatment option, are highly regarded; a personal understanding includes understanding how the disease may impact the specific woman rather than women in general	Created a system of connections within and outside the healthcare system to receive recommendations; made space and time to investigate; discussed to personal priorities; questioned aloud and overtly engaged in critical reflection; displayed an attitude of openness and curiosity about treatment options

Ways of Learning in Treatment Decision Making

Women constructed their treatment choices through the act of learning about cancer and treatment information from other people are resources. As shown in Figure 2, the ways of learning about cancer and its treatment were attached to what women believed to be authoritative knowledge about surviving cancer, that is, the knowledge that carried the most weight for these women, even when several knowledge systems may exist. Ways of learning were also attached to what women attributed value to, which represented their beliefs. Finally, women revealed their ways of learning through their described actions and the attitudes they displayed toward cancer and treatment information. In essence, the beliefs and values of women gave rise to their actions in learning about cancer and treatment information. Two main types of learning were present in the sample (Table 2). In this context, women learned about cancer and its treatment by: 1) trusting the healthcare system and/or 2) trusting a system of connections.

Learning by trusting the healthcare system: "I have faith in the system." As women described their many treatment decisions, the majority of decisions were made by trusting the healthcare system. This way of learning was rooted in a belief that the healthcare system holds authoritative knowledge about cancer and its treatment. The system is referred to here as the organizations, institutions, people, and resources that provide healthcare. For these women, the healthcare system is the key to specialized cancer knowledge; by accessing the knowledge available through the healthcare system, a woman would gain the best chance of surviving cancer. When learning about cancer and treatment in this way, women expressed favor toward the healthcare system and trusted the recommendations derived from this system. A 48 year old woman described her trust:

> “I had to have faith in the system. And what made me feel comfortable about it was that I know that they have so much experience dealing with breast cancer, that I’m gonna trust them and put my faith in them.” (Participant 21)

This way of learning in breast cancer was also founded on value attributed to the authority of persons in medical professions, which represented beliefs regarding the inherent goodness of education and training. Value was also attributed to the institutions and organizations, as well as the resources they hold; in particular, patients trusted the treatment guidelines and protocols that could be accessed by medical professionals. Describing what she trusts in decision making, a 55 year old woman said:

> “I’m relying on them [physicians] that they went to med school, that the Canadian government, through whatever, has set protocols… you know, the combinations and permutations of breast cancer are way more complicated than I realize… they’ve plugged my information into a machine and it spit out a treatment. I believe that today is the best treatment possible.” (Participant 7)

A major indicator of learning by trusting the healthcare system, was when women received cancer information and completed their treatment decision making within a single consultation appointment. Women did not describe other systems or connections with which they elicited information about cancer or its treatment in order to make a decision in these cases; instead, women relied on a dyadic relationship with their healthcare provider to provide all the information they would need to make a decision. While women were often accompanied by a family member or friend to the appointment, these women described loved ones as taking a supportive role in decision making and did not describe family members as directly involved in treatment decision making. Other actions were also indicative of this way of learning, including: not asking follow-up questions about the information, not discussing goals of care or personal priorities in treatment, and displaying an attitude of acceptance of the recommended treatment, even when the woman also described feeling frustrated with the experience and/or feeling resistant to undergoing the treatment.

Learning about cancer and its treatment by trusting the healthcare system occurred most often soon after diagnosis, when women were particularly overwhelmed and scared. At these times, most women were receptive and accepting of help from their healthcare providers, even if not fully understanding their cancer or treatment options. Being scared and needing help, a 35 year old woman explained her attitude of acceptance at her first consultation after diagnosis. Here, she received a recommendation to undergo chemotherapy as her first treatment and she said: "I was very resigned and kind of practical about it… it was very much kind of, tunnel vision or blinkers, it was like just get through" (Participant 1). Although this woman was disappointed that she would have chemotherapy so soon, she accepted the recommendations of her healthcare provider. For many women this resignation to the recommended treatment was often accompanied by some feelings of resistance since they "felt between a rock and a hard place" (Participant 18, age 66 years), or felt caught between the threat of disease and the threat of treatment – the possible short and long term negative impacts of treatment. Despite feelings of resistance to undergoing treatment, these women made a treatment choice by trusting the information learned in the appointment with the healthcare provider.

Trusting a system of connections: "I need to know about my cancer." At other times, women described making treatment decisions by trusting a system of connections made with other people and resources, beyond the healthcare system. This way of learning was rooted in a belief that a range of sources hold authoritative knowledge about how to survive cancer, and that people differ in what they need, even if their diseases are similar. One 40 year old woman said, “There’s best practices and there’s protocols and there’s all of these things, but there’s a reason they’re not called rules – it’s because everybody’s different… you can help each person individually” (Participant 20). Similarly, a 71 year old woman said, “It’s just like saying it’s a one-size-fits-all thing… you know, everybody will have different, I guess, priorities” (Participant 12).

This way of learning was founded on the value women attributed to gaining their own personal knowledge of their specific type, and subtype, of breast cancer. Value was also attributed to learning about treatment options, insofar as how these treatment options might impact women in the short and long-term. In order to understand these aspects of the disease and treatment, women utilized a range of sources to elicit information about cancer and its treatment. When a 43 year old woman was told she would not need chemotherapy, she asked to know how her medical oncologist came to that decision. The woman described her conversation with her oncologist when she questioned the oncologist’s decision not to offer her chemotherapy. She said:

> “[the oncologist said] ‘that’s why I went to school for this many years.’ And then you know we talked, and talked, and talked about how she came to these arrangements, but it’s like this online computer program that they plug my information into and then it kind of gives them the risk factors, and I, I understand that on a certain level, but ‘gosh I’d really love to see you work through the computer program with me’, or ‘I’d really, really like to have that decision reviewed by somebody else.’” (Participant 4)

Yet, for reasons unknown, the decision was not explained further with the woman, nor was the woman able to get more knowledge of the computer program that indicated that further treatment was not necessary. This level of information was not satisfying for this woman, and she went to sources outside of the healthcare system to work to understand her personal cancer diagnosis and how her cancer might behave, with or without chemotherapy. A personal understanding, as opposed to a general understanding, was valued by women who learned by trusting a system of connections.

Women who trusted a system of connections indicated this trust through their actions. These women showed an openness to treatment options and a curiosity – wanting to know *how* cancer behaves, *what* different treatments are offered, and *why* these treatments were offered. Women asked these things of their healthcare providers, yet they went beyond their connection with their provider. As such, a major indicator of this way of knowing were when women engaged with multiple sources of information outside the healthcare system, and when women described reflecting on those treatment options.

A range of sources were considered to be authoritative on cancer and its treatment, including: trusted and knowledgeable acquaintances, allied health professionals, second opinions from within or outside the local healthcare system, complementary and integrative health practitioners, and electronic and print resources. At times, women pushed for further medical testing (such as genomic testing) or sourced second opinions about diagnoses or treatment options. Women accessed, or worked to develop, a system of connections and relationships. As one 50 year old woman said, “I’m gathering all the information I can. You have to weigh and measure and choose the road that you think is going to be best for you (Participant 15). This was indicative of this way of learning for these women, who spoke of connecting to others outside of the cancer organization to elicit information about treatment.

This engagement with others beyond the healthcare systems could not take place without women taking space and time outside of appointments to choose a treatment. These spaces included homes and workplaces where diagnosed women would connect with others that were associated directly with the healthcare system. Other spaces were private spaces women found to reflect on the information that was shared with them. Time taken outside of appointments was largely described as time taken from women's other activities in life (work, family, recreation) that was redirected to be used to make connections with others in order to learn about cancer and treatment. Thus, time and space also indicated trusting a system of connections; however, the time and space used was not necessarily extensive, some women learned about cancer and its treatment, reflected on these choices, and then made a choice in a short period of time.

Shifting Between Ways of Learning

Women described a myriad of treatment decisions during data collection. Among the 22 women in this sample, 88 decisions were made between the time of diagnosis and the completion of treatment. By analyzing the major indicators described above, it was found that women learned by trusting the healthcare system in 63.6% of decisions and they learned by trusting a system of connections in 36.4% of decisions (Table 3). The statistics presented here represent the descriptions of women. Comparisons are made between groups, yet statistical testing did not occur due to the methodological design of the study and the sample size. As a result, it is unknown if any differences between groups is statistically significant.

There were slight differences between age groups as well (Table 4). First, women faced a different average number of treatment decision, dependent on their ages; younger women faced an average of 4.4 treatment decisions, middle aged women faced 4.2

treatment decisions, and older women faced 3.1 treatment decisions. Thus, most younger and middle aged women, on average, considered at least one more decision than the older group. Second, while most women learned about their first treatment decision by trusting the healthcare system, 48.4% of the decisions made by younger women were made by trusting a system of connections. This number decreased with age, with middle aged women and older women making less decisions this way (36.8% and 15.8% of decisions respectively). It is possible that women may use both ways of learning in a single decision, particularly if a decision can be broken down into discrete parts where learning about different information in different ways would be beneficial. Descriptions of this occurring did not arise in data collection and analysis. As a result, the main indicators were used in data analysis to classify each decision as either learning by trusting the healthcare system or learning by trusting a system of connections.

Table 3

Number of Decisions Made Per Way of Learning (% of Total Number of Decisions)

Decision	Trusting the healthcare system	Trusting a system of connections
Surgical*	23 (26.1)	10 (11.4)
Chemotherapy	10 (11.4)	8 (9.1)
Radiation	13 (14.8)	3 (3.4)
Hormone Therapy	10 (11.4)	8 (9.1)
Other**	0	3 (3.4)
Total	56 (63.6)	32 (36.4)

Notes:
*lumpectomy, mastectomy, reconstruction, no reconstruction
**clinical trial, traditional healing practices

Table 4

Numbers of Decisions and Ways of Learning by Age Group (%)

Ways of learning	Total	Younger (N=7)	Middle (N=9)	Older (N=6)
All	88	31 (35.2)	38 (43.2)	19 (21.6)
Trust healthcare system	56 (63.6)	16 (51.6)	24 (63.2)	16 (84.2)
Trust system of connections	32 (36.4)	15 (48.4)	14 (36.8)	3 (15.8)

Learning about cancer and its treatment was cyclical and non-linear. It was cyclical because decision making was a repeating process, consequently, women were able to become more practiced at decision making in cancer over time. The process was non-linear because, although women used more than one way of learning, ways of learning did not move in one direction. For example, ways of learning did not move from learning by trusting the healthcare system toward learning by trusting a system of connections. The movement between ways of learning was fluid rather than directional. For example, as women made their first decisions after their diagnoses, all but one woman learned about treatment information by trusting the healthcare system; then, later in the cancer experience, many women shifted their way of learning to trust a system of connections in decision making, and no longer relied on the healthcare system to be the sole source of cancer and treatment information. However, for later decisions, some women again learned about new cancer and treatment information by trusting the healthcare system. These changes were noted particularly when women were still in active treatment and were able to participate in follow-up interviews. At times, this follow-up interview provided an opportunity for these women to describe the process of changing their minds about treatment. For women who had completed treatment at the time of their initial interview, a follow-up interview did not produce data regarding these changes.

Influencing a shift toward trusting a system of connections. The movement toward learning by trusting a system of connections was influenced by a variety of forces. First, some women worked to develop a system of connections where they had none before, particularly as they gained experience in learning about cancer treatment and met other women with cancer. Yet, it was not only the ability to access other sources of information that enabled a woman to shift her way of learning; in several instances, these shifts were due to the cancer experience itself. For example, at times women experienced an awakening of their identity/self/voice as they experienced cancer. As women awoke to their new existence with cancer, some shifted to learning by a system of connections and found their "voice." If they had previously been unsure of how to ask questions, or tell someone they needed help in decision making, these women were able to say what they needed and connect with other people and resources. A 42 year old woman said:

> "I have always been on my own - doing things, making decisions on my own. So having the cancer and being in a system where you absolutely have to get help, and have to ask for help was like, how do I do that? So I had to actually learn how to find a voice." (Participant 5)

Also, most women reflected on their personal priorities due to the cancer experience. These women were influenced by the desire to match their personal priorities to their decisions. These priorities were not necessarily acknowledged by women at the outset of cancer, but became known to them as they proceeded through the cancer experience. For example, many women came to recognize and prioritize their roles as a result of cancer. When this occurred, women's multiple identities influenced the way they learned about cancer treatments; women sought information from others who could help them know more about how treatment might impact their ability to carry out their roles in the future. A 64 year old woman talked about being a mother and grandmother, then she said: "My family's important. I want to be, I guess I want to be alive. You know, to see them grow and see their, my grandchildren grow" (Participant 8). Similarly, a 32 year old woman explained that she identified strongly as a mother. She had four children before her diagnosis and she desired more children. She said:

> “They (physicians) told me I had the option, if I didn’t take the chemo. Then there was, like, a really big chance that I could die. And they told me if I took it, then, like, there was a really big chance that we would have only four kids… I love my kids very much and I have four, somebody needs like to look after those four that we have.” (Participant 19)

At times, recognizing personal priorities after treatment led to regret or, when possible, women changing their treatment plans. Times of regret and/or change in treatment precipitated by a shift in their way of learning in cancer. In these situations, women developed (or accessed) a larger system of connections to learn about cancer and its treatment, they reflected on their experiences and their future hopes, and they began to voice their concerns that the treatment choices made earlier did not match their current wishes. Some of these women voiced regret over an earlier choice which could not be undone, being dissatisfied with the way treatments was recommended. An 80 year old woman spoke of her regret at undergoing a lumpectomy instead of a mastectomy. She said:

> “I didn’t get a full explanation of what was involved [in treatment], what could happen, and what couldn’t happen, and all that kind of stuff…if I had got a full explanation of the radiation, then I wouldn’t have backed down from the mastectomy.“ (Participant 22)

Influencing a back-and-forth movement between ways of learning. Not all women moved toward learning by trusting a system of connections; some women moved back-and-forth between ways of learning. Women in these situations described several influences which precipitated the shift from learning by trusting a system of connections, back to trusting the healthcare system. First, there were occasions when women learned about a treatment choice through a system of connections and then experienced good outcomes from this treatment. Some of these women then processed their next treatment decision by trusting the healthcare system. Second, some women were influenced by the exhaustion experienced from continually developing connections for multiple decisions. This work took a toll on women overtime, and they began to feel too tired to continue to develop a system of connections for all of the decisions encountered. A 40 year old woman explained that she would typically push to learn more about the treatments she was offered, but she would get tired of pushing. She said, “I know that I have a very strong voice and I don’t let things go, (but) sometimes I’m too tired” (Participant 20). Third, when women experienced new and frightening information about their cancer diagnoses, the influence of fear shifted women toward learning by trusting the healthcare system by stopping women from connecting to a larger system of cancer information. A 55 year old woman explained that she was planning on seeking alternative treatment information from a naturopath, but stopped when she was given a poor prognosis because she became too scared to try an alternative therapy. She described the appointment where her oncologist told her the seriousness of her cancer diagnosis. She said:

> “I was a good little girl, I just went, ‘Whatever I have to do, like I really do wanna live here.’ So it certainly snapped me into reality. Like, I gave up on the naturopath and I agreed (with recommendation). And I got the six (chemotherapy) treatments.” (Participant 7)

Discussion

Study findings showed that women's ways of learning about breast cancer and its treatment were founded on their beliefs and values, specifically women's beliefs regarding authoritative knowledge about surviving cancer. Two ways of learning were presented here – learning by trusting the healthcare system and learning by trusting a system of connections. These ways of learning were not static during the cancer experience.

Concerning existing learning theory, women's ways of knowing (Belenky et al., 1997) and women as learners (Elisabeth Hayes & Flannery, 2000) offer a starting point. These theories discuss women as knowers and learners in formal and nonformal adult learning contexts, and have provided a fundamental understanding of how women know and learn. In particular, these theories have put forward the uses of inner voices (a deeply personal, subjective, intuitive "voice") and outer voices (listening to friends and/or authorities) in how women know (Belenky et al., 1997); they have also emphasized the role of relationships in learning (Elisabeth Hayes & Flannery, 2000), and have encouraged researchers to consider the social contexts of women's learning (Elisabeth Hayes & Flannery, 2000).

Other learning theory that is applicable is informal and incidental learning theory (Watkins & Marsick, 1992), where incidental learning is thought to occur on a continuum of consciousness and intentionality. This learning may not have a specific goal or be deliberately planned, yet learning is a by-product of other experiences. Other related learning theory includes self-directed learning (Candy, 1991; Knowles, 1950), reflection in action (Schön, 1983), and social modeling (Bandura, 1986). The learning activities described by women may also be described as problem-based learning (Merriam &

Bierema, 2014), where learning occurs through solving a problem – in this case, the problems include deciding between treatment options.

Keenly different from earlier works that focus on formal and nonformal learning, is that this present study conceptualizes ways of learning that are incidental in nature. Even when patients discussed decision options with healthcare providers, descriptions of healthcare providers as facilitators of learning was lacking. These findings promote an awareness of lifelong learning activities which humans face in other contexts (Coombs, Prosser, & Ahmed, 1973), including the context of medical decision making.

Further, the idea that beliefs, values and attitudes guide the actions and intentions of individuals is well known and have been theorized (Ajzen, 1985; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975), and yet this model is a unique application of these concepts to learning in illness. In this study, beliefs and values concern authoritative sources of knowledge, and were powerful influences in guiding the decision making actions and attitudes of women with breast cancer. Specifically, for many of these women, the healthcare system held authoritative knowledge about surviving cancer; while, for other women, authority did not rest with the healthcare system alone, these women also acknowledged the authority of other women and other sources external to the local healthcare system. At times, women also described looking to an internal authority, or an internal "voice," that helped them to know what decision to choose.

These present findings point to the interest or ability of the patient to network, often directly with persons, but also by navigating resources. Learning through connectedness and relationships is consistent with other women's learning and knowing theories (Belenky et al., 1997; Flannery, 2000). Godbold (2012), asserts that relationships in the context of healthcare enables the process of sense-making, and that sense-making is necessary in ongoing information sharing; patients make sense of highly complex situations and information by interacting with others (Godbold, 2012; Weick, 1995). These present findings support the concept of sense-making through connectedness to others, and add to this literature by presenting the need for many women to broaden their interactions beyond the patient-provider relationship. In this way, women may undertake sense-making activities which encompass many connections in their social worlds.

Finally, these findings point to questions regarding patient engagement and autonomy. Where engaging patients in their own healthcare is associated with improved quality of care (Coulter, 2011), these findings do not suggest that patients desire complete autonomy. Many women valued a collaborative relationship with healthcare providers when decision making took place. As well, these findings do not suggest that patient engagement is dependent on one particular way of learning in breast cancer, or that one way of learning in breast cancer is preferred over another. To do so would suggest that some learners are not engaged in their care, and it would put women in danger of being reduced to generic categories of learners, perhaps leading to judgements placed on their ways of learning in cancer. This would do a disservice to women who are working to develop ongoing understandings of their diagnoses and treatments over time, all the while coping with the physical and psychosocial ramifications of their diseases. Instead, these findings suggest that women have different ways of learning, and that, due to a number of factors, an individual woman may move between ways of learning as she is working to make sense of her disease and treatment.

Implications for Practice

The authors suggest that women’s learning in breast cancer primarily occurs in a social context and women want conversations about cancer and its treatment. Where making sense of a disease and its treatment happens over time, healthcare systems could do well to provide opportunities for all women to access information at several points during the cancer experience. Assisting women in expanding their connections may best be done by providing interprofessional models of care in breast cancer; with an increased number of professionals involved in the care of the patient, before treatment decisions are made, a greater likelihood exists that a network of connections will be expanded for the woman at the centre of care.

Also, healthcare providers can increase their permissiveness in “allowing” patients to explore learning about treatment outside the healthcare system (e.g. alternative treatment options). By being open to communicate with patients about patient connections outside the healthcare system, healthcare providers can increase the likelihood that patients will be forthcoming about their fears related to treatment, as well as their goals and wishes over time. Doing so will increase information support and expand patient opportunities to learn about cancer and the medical treatments offered, if they so desire.

Finally, women’s learning in this context may benefit from informal opportunities to learn about cancer and its treatment, prior to the point of decision making. When better understanding the learning experiences of women, informal learning strategies could be developed, and employed, to enable women to learn in this context. Informal learning opportunities have the potential to influence patient content knowledge and attitudes toward treatment decision making.

Implications for Research

These findings provide fundamental knowledge about ways women learn in breast cancer, and may to encourage further research on patient learning in the context of illness.

A more detailed exploration of the utility of a gender analysis would continue to benefit this area, since there is much to be learned about the influence of gender on incidental learning throughout the lifespan. In particular, these findings point to the usefulness of a feminist perspective in further research in this area, since core concepts of feminist thinking were present (e.g. connectedness to others and organizations; use of voice). Using a feminist perspective could lead to the development of gender-sensitive theory in treatment decision making (Im & Meleis, 2001); where gender is a basic feature of the research, the diversity and complexity of women's experiences are highlighted, and the sociopolitical contexts and constraints of women's experiences are more closely reflected upon. The goal of developing gender-sensitive theory is to empower women and to promote guidelines for raising consciousness (Im & Meleis, 2001).

Also, reconceptualising research on information support to include research on *learning* in the face of life-threatening illness, will move learning theory into spaces where, traditionally, learning theory has not entered. Similarly, exploring learning in the context of illness will move learning theory toward a more holistic view of women's learning (E. Hayes, 2000).

Finally, research on ways of learning in cancer would benefit from involving women of diversity (e.g. cultural, sexual, religious), taking care not to impose the experiences of one group of women on any other future study groups. In this way, the model describing ways of learning can be strengthened, and a larger typology of ways of learning can be drawn upon when designing future patient education activities and materials.

Limitations

This study has limitations in that the findings describe the experiences of women living with breast cancer in one jurisdiction, and are a reflection of the women within this jurisdiction. Also, other ways of learning in breast cancer may exist since some treatment decisions may not have yet been faced by women at the time of data collection. Similarly, no participants in this study refused all cancer treatment; all women involved were working with the healthcare system to some extent to receive care for their cancers. As a result, the two ways of learning in breast cancer presented here are a starting point in a typology of ways of learning, which can be added to by further research. Also, Learning about cancer and its treatment may have functions beyond constructing a treatment choice, including assisting in coping with cancer (Baumgartner, 2011). Women in this study did not describe the function of learning beyond constructing an understanding of their diseases or construction treatment choices. However, both the act of avoiding and seeking health information may be closely related to coping behaviours (Case, Andrews, Johnson, & Allard, 2005).

Conclusion

Women's ways of learning in breast cancer, as it relates to the experience of treatment decision making, is founded on the beliefs and values of women about authoritative knowledge in cancer. A model depicting the ways women learn in this context was presented. Two ways of learning were highlighted, that is, women learned by trusting the healthcare system and/or they learned by trusting a system of connections. As women faced multiple treatment decisions, many women shifted back-and-forth between these ways of learning.

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CHAPTER 6: BARRIERS TO INFORMATION SUPPORT

Abstract

Background: Most patients with cancer want information about their disease, its treatment, and the consequences of treatment. As a result, information support must be provided throughout the cancer experience; however, it is unclear if there are barriers to information support during the cancer experience, or if younger and older women experience these barriers differently.

Purpose: To explore the experience of decision making in breast cancer across the lifespan, paying particular attention to treatment decisions early in the cancer trajectory. This paper discusses findings specific to the barriers patients experienced to information support in breast cancer.

Method: Data collection and analysis followed the tenants of constructivist grounded theory. Semi-structured interviews were conducted with 22 women with invasive breast cancer. The average time from diagnosis was 9.5 months and the average participant age was 55 years (range of 32-80 years). Participants were grouped in three subgroups: younger women, under 45 years (N=7); middle-aged women, aged 45-64 years (N=9), and older women, aged 65 and older (N=6). Interviews were an average of 67 minutes in length and explored the experience of treatment decision-making through open-ended questions which sought the details about the context of decision-making, the process of decision-making, and how a woman’s age influences her experience. Data was organized using ATLAS.ti software and analyzed using constant comparisons at the individual level, subgroup level and as a whole.

Findings: Women of all ages have information support needs in breast cancer. Barriers to the provision of information support include: 1) emotional distress; 2) patient-provider communication; 3) provider-provider communication; 4) making it personal, and; 5) access to information. Similarities and differences between younger and older women are addressed.

Conclusion: Women want information about their cancer and its treatment regardless of age. Barriers to information occur at various levels, such as at the level of the individual patient, the provider, and the health system. Implications for research include the need to study the influence of emotional distress on understanding information prior to treatment, as well as research about communication skills training for healthcare providers. Implications for practice include implementing interprofessional models of care so that patients’ information needs can be better met within the cancer care context and patients can be empowered to make satisfying treatment decisions that are consistent with their individual wishes.

Background

In general, patients with cancer require detailed information about their type of cancer and prognosis, their treatment options, the potential consequences of treatment, and information to help in coping during and after treatment (Ankem, 2006; Cox, Jenkins, Catt, Langridge, & Fallowfield, 2006; Morrison et al., 2012; Squiers, Finney Rutten, Treiman, Bright, & Hesse, 2005). While individuals may have different needs regarding the level of detail of information, there is a continued need of information support for most patients throughout the cancer trajectory (Matsuyama, Kuhn, Molisani, & Wilson-Genderson, 2013; Rutten, Arora, Bakos, Aziz, & Rowland, 2005), whether the patient is newly diagnosed, in treatment, post-treatment or at end-of-life.

Fulfilling the information needs of patients is associated with several benefits, including increased patient satisfaction and perceived better quality of care, increased patient involvement in decision making (Luker et al., 1995), psychological wellbeing (Husson, Mols, & Poll-Franse, 2010; Mistry, Wilson, Priestman, Damery, & Haque, 2010), increased coping during cancer and reduced anxiety and mood disturbances (Ankem, 2006; Arora et al., 2002; Jefford & Tattersall, 2002; Johnson, Nail, Lauver, King, & Keys, 1988), and improved communication with family members (Arora et al., 2002; Reynolds, Sanson-Fisher, Poole, Harker, & Byrne, 1981). When these multiple benefits can arise from meeting the information needs of patients, quality health care depends, in part, on understanding what patients with cancer want to know and providing that information at an opportune time (Rutten et al., 2005).

Most patients want a minimum of basic information about their diseases and treatment options (Leydon et al., 2000) and yet evidence shows that these information needs are being met with varied success. In a systematic review of information needs of cancer patients (Rutten et al., 2005), the authors created a typology of information needs, consisting of 10 categories with 64 subcategories. Analysis showed 15.3% of patients need cancer-specific information (e.g. stage of disease, specific diagnosis information) and 43.8% need treatment-related information (e.g. available treatments and treatment options, side effects of treatments). Specific to radiation oncology, a study examining the symptoms and information needs of patients undergoing radiation therapy (Güleser, Taşci, & Kaplan, 2012) showed that more than 50% of radiation oncology patients did not receive treatment information before undergoing radiation treatment. Then, if experiencing complications due to treatment, 83% of these patients wanted more information. More local to this present study, a Canadian patient satisfaction survey across five provinces (Canadian Partnership Against Cancer, 2015) showed that, of adults receiving active treatment in an ambulatory setting, between 7.4% and 11.6% of these patients responded negatively to a questions regarding the provision of information, communication and education in their cancer setting.

Where there is variation in information support, other possible differences in patients is of interest. Patients will have differing diagnoses and are at different stages in the continuum of care, influencing their information needs (Matsuyama et al., 2013; Rutten et al., 2005). There may be other differences which point toward the makeup of the individual, such as differing needs about the level of control a patient wishes to have over information (Ankem, 2006; Hack, Degner, & Dyck, 1994). Other demographic characteristics may be of interest in the understanding of information needs in cancer as well, such as level of education, gender, ethnicity and age of the individual (Jacobs-Lawson, Schumacher, Hughes, & Arnold, 2009; Mistry et al., 2010).

With existing literature pointing to the cancer experience being different for younger and older persons (Mor, Allen, & Malin, 1994; Stava, Lopez, & Vassilopoulou-Sellin, 2006), investigating the experience of decision making across the lifespan is warranted. Prior research shows that younger adults with cancer may have an increased need for information compared to older patients (Ankem, 2006; Goldfarb & Casillas, 2014), yet the reasons for this are unclear. Regarding older adults with breast cancer, one study looking at the information need of older women with early stage breast cancer (Presutti et al., 2014) showed that the majority of patients were satisfied with the information support received during treatment, yet desired a higher level of support when making treatment decisions. Nearly half of these patients were not provided choices for different treatment options, and 85.6% of patients wanted to ask more questions after leaving their consultation appointments (Presutti et al., 2014). An examination of the differences in needs across the lifespan is warranted when patients may already struggle to recall cancer-specific information provided to them by healthcare providers (Hack et al., 1994; van der Molen, 1999), without the added difficulties that may be experienced due to further functional decline, co-morbidities, or decreased cognitive and sensory functions that can occur due to aging (Greene & Adelman, 2003; Kessels, 2003; McGuire, 1996). For these patients, their ability to recall information may influence decision making, adherence to treatment and their overall satisfaction with care (Kessels, 2003; McGuire, 1996).

Most studies on information needs are quantitative in nature with few exceptions, yet there is a need to understand the patient experience through qualitative means that seek to have patients voice their own concerns, including the experience of information support. As a result, this paper discusses findings specific to the barriers patients experienced to information support in breast cancer. These findings were derived from a study that explored the experience of decision making in breast cancer across the lifespan, paying particular attention to treatment decisions early in the cancer trajectory.

Method

This qualitative, grounded theory study used a constructivist approach (Charmaz, 2006) and guided the methods chosen. Lifespan and gender perspectives guided the construction of the study interview guide, determined the recruitment strategy and influenced the decision to analyze the data by age groups.

Participants were women diagnosed with breast cancer of any stage or subtype. To be included in the study, women needed to be diagnosed within one year or be within one year of completing cancer treatment. Women were excluded if they had a cancer recurrence. Participants were recruited from ambulatory care settings and were formed into groupings of younger women (under 45 years old), middle aged women (45 to 64 years old), and older women (65 years old and older). These grouping were based on previous research (Stava et al., 2006), as well as the clinical experience of healthcare providers involved in study recruitment. Initial and theoretical sampling dictated study recruitment. Recruitment ended when no new information was forthcoming. Two authors (HCE and RW) analyzed the data and decided that theoretical saturation had been reached.

The study sample included 22 women (Table 1) who participated in 29 interviews (22 initial interviews, 7 follow-up interviews). Women ranged in age from 32 to 80 years (average age of 54.59 years). Data was analyzed at the individual and whole group levels. However, because the age of women was of interest in this study, participant data was also grouped by age. Participants included younger (N=7), middle aged (N=9) and older (N=6) women.

Table 1

Participant Ages and Stage of Cancer

	Total	Younger	Middle Age	Older
No. of women	22	7	9	6
Average age* (range)	54.6 (32-80)	39.3 (32-43)	54.8 (48-64)	72.2 (66-80)
Diagnosis stage**				
Stage 1	7	2	4	1
Stage 2	8	1	3	4
Stage 3	6	4	1	1
Stage 4	1	0	1	0

Notes:
*in years
**self-reported
Younger: Age ≤ 44 years
Middle age: Ages 45 – 64 years
Older: Ages > 65 years

The time since diagnosis until the first interview was from 1 to 31 months (average of 9.45 months since diagnosis) and women described a total of 88 decisions made. Most women were married or in common-law relationships (N=14). Women identified themselves to be of European (N=14), Aboriginal (N=2), East Indian (N=1) and Caribbean (N=1) decent. Four women did not indicate their ethnicity or cultural group.

Data was collected via demographic questionnaire, semi-structured interviews (Figure 1), and field notes. Women were asked about their perspectives of being women of their ages making decisions in breast cancer. Barriers to information needs were specified in the question guide, however these findings emerged as a part of women describing the experience of treatment decision making in this context. All data was collected by the first author (HCE). Women were offered the opportunity to provide follow-up information in a second interview. The average interview length ranged from 36 to 131 minutes, with an average length of 67 minutes.

Figure 1

Interview Guide

1. What was life like before you were diagnosed with cancer?
2. What was it like to be diagnosed with cancer?
3. What has happened since you were diagnosed?
4. What is a decision making experience that you would like to tell me about?
5. Can you tell me about any treatment decisions?
6. Was there a decision that you felt you were unable to make, perhaps you felt stuck or unable to act?
7. Earlier you mentioned (decision), can you tell me more about that?
8. Is there an issue that you are currently making a decision about?
9. What do you think people should know about women your age and making decisions after a breast cancer diagnosis?
10. Is there anything else I should know to help me better understand decision making in breast cancer?

Data analysis was conducted by the two authors (HCE and RW) and occurred concurrently with data collection. Demographic information was analyzed as basic descriptive statistics. Field notes were attached to interview transcriptions and uploaded into a data analysis software (ATLAS.ti). The constant comparative method of analysis was used to analyze data emerging from the field notes and interviews. Transcripts were read and re-read and constant comparisons (Charmaz, 2014) were made within and between interviews across the whole sample. A lifespan perspectives was utilized in data analysis, therefore interview data was also analyzed within and between age groups. Data was coded during focused and theoretical coding stages and included initial, process, values, pattern and versus coding (Saldana, 2012). Memo-writing helped to raise codes to categories and enhanced the development of theory (Charmaz, 2014).

Ethical approval was obtained from the University of Manitoba's Research Ethics Board (ENREB) as well as the impact committees where recruitment took placed (CancerCare Manitoba, Winnipeg Regional Health Authority, Southern Health-Santé Sud). Prior to consenting to participate, participants were provided information about the study and had opportunities to ask further questions. Written consent was obtained before any data was collected.

Findings

Women indicated that they experienced barriers to the provision of information support in treatment decision making. Information support was needed when attending consultation appointments at diagnosis, when primary therapy is considered, and in the event of considering adjuvant treatment. Data analysis revealed five main categories of barriers to information support. These barriers include: 1) emotional distress; 2) patient-provider communication; 3) provider-provider communication; 4) making it personal, and; 5) access to information. The information support needs of younger, middle-aged and older women are addressed as well.

Barrier 1: Emotional Distress

The emotional distress experienced by women in breast cancer is a barrier to information support because this distress influences women's receptivity to new information, as well as the ability for women to retain the information after their appointments. Women described the experience of being diagnosed as a time of heightened emotional distress, conveying the emotion by using words such as "scared," "overwhelmed" and "fearful." This emotional state, brought on by the cancer experience, created a context where it was difficult for women to receive and/or retain new information.

A 55 year old woman described her diagnosis, saying that she understood she was being diagnosed when she was given a package of information about breast cancer. She admitted that her emotions prevented her from asking questions to help her understand what was going on, she said:

> "I looked, and it was a package [to explain] what a woman does when she's, you know, got breast cancer. But no one really said it to me [the diagnosis], and I never asked… you know, you're still reeling." (Participant 7)

Another woman identified that she was very scared after diagnosis, scared of dying from cancer and scared of the effects of treatments. This fear prevented her from discussing chemotherapy with her oncologist. She spoke of her emotions when she explained:

> "I mean a lot of people have had cancer, a lot of people have had chemo… but it was still like I was, I guess I was, scared. I was actually scared of having poison injected in my system, I really think that was the thing." (Participant 9, age 59)

One 74 year old woman observed her emotional distress at diagnosis. She said, “you’re so overwhelmed. You’re overwhelmed, you’re scared, you’re fearful, you’re – all those senses are just going, [the senses are] ramped” (Participant 13). Like many women, these emotions affected her ability to receive and clarify cancer information. She added, “I understood I had cancer. I don’t know, I didn’t know much about cancer. I really didn’t understand a lot. Just fear” (Participant 13). In the end, this woman agreed to the treatment recommended by her healthcare provider. However, not understanding basic information about cancer and its treatment had consequences later in the cancer experience; several months after, this woman tried to understand why she did not feel well when taking hormone therapy pills, and it was only in a conversation with her pharmacist that she realized that the prescription was a part of cancer therapy. She said, “I didn’t know the pill was chemo, I thought it was a heavy duty vitamin. It sounds silly, but I didn’t know” (Participant 13). This woman admitted that she might have been told this information early after diagnosis, but she did not remember being told.

Other women described the emotional toll that the cancer experience takes on women, due to the many worries faced in cancer. This emotional toll influenced the women’s ability to attend to information over the course of treatment decision making. A 35 year old woman reported:

> “There’s anxiety that comes around in terms of, if it [cancer] comes back, but also kind of like, the impact of it: money worries, impact on my kids… impact on future life, relationships… and just kind of like an emotional, like exhaustion. Like an emotional exhaustion.” (Participant 1)

Women struggled to verbalize what they attributed their fears to in specific situations in cancer, yet women revealed that they have multiple worries throughout the experience.

Barrier 2: Patient-Provider Communication

Communication challenges between the women and their healthcare providers were a barrier to understanding information about cancer and its treatment. These included the use of medical jargon, the omission of treatment information during consultations, and a perceived lack of empathy during the patient-provider encounter.

First, women struggled to understand their specific diagnoses, stemming from the use of unfamiliar medical jargon in consultation appointments and on pathology reports. A 48 year old woman described the experience of reading her own pathology report, an experience marked by confusion and frustration as she struggled with the terminology used in the report. In an effort to understand more, this woman attempted to speak to her surgeon, oncologist, and the oncology nurse about the report. However, these attempts did not result in a better understanding of her diagnosis. She explained:

> “I didn’t really know how to read that pathology thing… I wasn’t sure and no one was giving me clear answers. I’m like, ‘I don’t understand where was it? Is it DCIS? Is it… where is it?’ Nobody was giving me clear answers. I read all the pathology report, I couldn’t understand it. So I had phoned and talked to the nurse again and I was, ‘You know I don’t understand. I wanna know – yes I know it was metaplastic carcinoma, yes I know it was invasive and it was grade. And I know what you’re saying about my responses to those hormones including HER2 and all those things. But I don’t understand, am I triple negative, was it disitsu? Where is it? Like I don’t understand that.’” (Participant 21)

Eventually, this woman’s oncology nurse sent her to another location where a nurse navigator provided another explanation of the report. The women added, “she [nurse navigator] made me feel a lot better and [helped me] understand my situation a lot more." The medical jargon encountered in the beginning phase of cancer was problematic. She commented, "I would have preferred communicating [with] a little bit more clarity, and [not at] such a high level."

Second, women described not understanding the whole approach, or the full inventory, of probable treatments in breast cancer. Women attributed these misunderstandings to providers omitting treatment information during consultation appointments. For example, when women faced surgery as their primary treatment, many women did not have a full understanding that adjuvant treatments may follow surgery, and what treatment might entail. In these cases, when other treatments were offered, particularly chemotherapy, many women were bewildered and upset. To illustrate, a 58 year old woman initially believed her treatment would be limited to a lumpectomy and radiation therapy. However, after the lumpectomy, her healthcare provider offered chemotherapy; the woman then struggled with the decision whether or not to have chemotherapy since she perceived this treatment would not be needed from the outset. She said: "I was so confused because I kept saying, 'No, I don't need chemo, why would you [the oncologist] do chemo?' It was a really gruelling time" (Participant 9).

Another woman described assuming she would have a mastectomy, without other treatments, because the surgeon focused on surgical treatment in the consultation, and did not discuss the likelihood of later chemotherapy or radiation therapy treatments. This woman described going to the next consultation appointment to discuss breast reconstruction with a plastic surgeon. There, the plastic surgeon referred to the woman's chemotherapy treatments after surgery. The 55 year old woman said:

> "'I have to have chemo?!' I look back on it now and if I hadn't remembered what I actually said, I wouldn't believe that I didn't understand. But I didn't. I didn't know that A, B and C is equal to D. You know, someone has to tell you right? And I think what happened was the surgeon who probably should have been the [one]… I think he was trying to give me information in stages, and he just hadn't revealed that to me." (Participant 7)

This woman, like others, understood that the timing of cancer communication is complex for healthcare providers. However, she also felt that the omission of treatment information was problematic, even if the intention may have been to relieve her of the burden of too much treatment information at one time.

Several women experienced confusion and frustration due to the lack of communication about the range of treatments that might be offered during the course of the cancer experience. One older woman had initially wanted a mastectomy, yet during the course of the surgical consultation she was persuaded to have a lumpectomy instead. However, it was only after surgery that she realized that radiation therapy was a suggested treatment when lumpectomy is undertaken. This woman wished she had better understood how cancer was treated before choosing her primary treatment. She explained:

> "I didn't get the full explanation of what was involved, what could happen and what couldn't happen and all that kind of stuff. Until I was at the point of going for radiation. Because I think if I had got a full explanation of the radiation, then I wouldn't have backed down from the mastectomy… at that point – which I feel extremely strongly about –somebody, somebody needed to tell me exactly what the radiation entailed. The pros and cons. The aftermath... Because after the surgery, whatever you've chosen, you've chosen. So I think it's necessary to do

> the total explanation before the surgery. It is overwhelming, but it's the only chance that you are going to have to really make the decision." (Participant 22, age 80)

Barrier 3: Provider-Provider Communication

Women perceived a lack of communication between healthcare providers, which resulted in a barrier to information support. Specifically, women wanted their healthcare providers to communicate with each other about treatments, so that the women are provided comprehensive information about their cancer and its treatment.

Overall, women felt many healthcare providers did not attend to the larger impact of breast cancer on the individual. As a result, women did not receive treatment information in a comprehensive way. While women saw their treatment experience as a series of interconnected treatments, they did not see evidence that healthcare providers recognized this interconnected nature of cancer treatment. A 40 year old woman commented on her experience:

> "I kind of feel like along the way everybody has their job. Like the surgeon cuts and the, this person that, and this person that, but they aren't really concerned about what happens outside of that. They are in their bubble and while I appreciate they're experts on what they do, but nobody's just one thing. I'm just not a cancer patient." (Participant 20)

Another woman described her experience of getting information from healthcare providers about her cancer and possible treatments, likening it to a jigsaw puzzle. She desired to see the whole picture of cancer and treatment information, but was not in control of the puzzle pieces. She said:

> "Nobody really gives you all the pieces of the puzzle. You get a couple pieces from one person, couple pieces from somebody else… at the end of the puzzle you're still missing a whole bunch of pieces and you don't know where the hell they are." (Participant 6, 48 years)

As a result, women felt they understood cancer and its treatment partially, rather than fully, and women experienced confusion and frustration about possible future treatments.

This lack of communication between healthcare providers created incidents where women experienced inconsistent messages about cancer information. The lack of communication between providers was the source of much distress for women, especially when healthcare providers disagreed with each other about diagnoses and/or courses of treatment. A 35 year old woman said:

> "It was a bit strange to kind of hear information piece meal, or kind of different doctors saying slightly different things. You start to question. Maybe I don't need to go through chemo? Maybe I don't have to have all this poison pumped through my body? Maybe I don't have to lose my hair and go through the trauma that chemo is." (Participant 1)

As a consequence, these women had a general sense of unease about their courses of treatment, wondering if they were being aggressive enough with treatment, or if they were being more aggressive than necessary to survive cancer.

When women related their experiences of treatment decision making, it was common to hear women describe inconsistent messages from multiple providers. Less common, but still present, were descriptions of complete disagreement between healthcare providers. However, these occurred in cases where one healthcare provider disagreed with another provider's assessment of the diagnosis and/or treatment plan. In these situations, women were caught between providers, and needed to ask that the providers speak to each other directly to help facilitate a treatment decision. For example, a woman experienced fluid on her lungs after surgery, and her healthcare providers had differing opinions as to whether the fluid was a side-effect of surgery, or if it indicated metastatic breast cancer. The woman reported that each healthcare provider told her their assessment of the source of the fluid, the possible prognosis, and how to treat her discomfort; yet these assessments differed substantially, and the providers did not discuss the situation with each other. As a result, the woman was caught between the opinions of her healthcare providers, unable to move forward with treatment. After much confusion and physical discomfort, in addition to the distress associated with the thought that her cancer was at an advanced stage, this woman insisted her healthcare providers contact each other to discuss the situation. She described her experience:

> "I got really angry. I had a really bad night. And the next morning I phone my surgeon and said, 'What the hell's going on here? You're telling me it's just fluid build-up, not even to have it touched, he [the oncologist] is telling me he thinks I'm terminal. You two need to figure this out.'" (Participant 7, age 55)

As a result, her healthcare providers discussed the woman's symptoms and a course of action. In the end, the fluid was drained, not only providing relief from the discomfort, but also the confirmation that cancer cells were not found to be present in the fluid. A treatment plan could then be made based on this information.

Barrier 4: Making It Personal

Issues involving making care personal were barriers to information support for women with breast cancer. "Making it personal" includes instances when women perceived healthcare providers making care *too* personal, as well as instances when women perceived that care was *not personal enough*.

First, at times, information provision was made too personal – information was provided to women by using emotional language that evoked a sense of emotion, or closeness, between the healthcare provider and the diagnosed woman. In this way, the provision of cancer information was too personal and prevented women from accessing all of the information that they may have wanted, including the information that might help these women make a treatment decision that matched their individual wishes.

For example, one woman said that she did not want to take hormone therapy but, “he [healthcare provider] seemed to be fairly adamant about that… he actually said he couldn’t sleep at night if he knew I wasn’t taking this drug” (Participant 7, age 55). This woman appeared pleased that her oncologist seemed so invested in her health, yet her wishes for treatment did not match the wishes of her healthcare provider. In the end, she said that she found it difficult to continue asking for more information and she took the hormone therapy medication.

Similarly, a 71 year old woman described trying to decide if she would undergo a lumpectomy or a mastectomy and she said: “he [healthcare provider] said, ‘if you were my mother, my daughter, my wife, I would go with that [lumpectomy]’” (Participant 12). Even though this healthcare provider did not know the personal wishes of the patient in the same way he would likely know the wishes of his mother (or daughter or wife), this was the strategy used to recommend treatment to this woman. She said that she decided to have a lumpectomy at that point of the discussion. Emotional language was persuasive if used while providing treatment information. While some women seemed to appreciate the personal connection, and others felt manipulated by the personalized approach, the use of emotional language shifted women's focus from developing an informed understanding of how cancer treatment may impact their lives as individuals, to a focus on how the healthcare provider felt about treatment.

While treatment information can be too personal, there are other incidents when the provision of treatment information was not made personal enough. In these cases, either healthcare providers were perceived to be overly reassuring while providing information, or they were perceived to be lacking empathy for the patient as a person.

In some instances, women perceived that cancer and treatment information was provided in overly reassuring ways that focused on good outcomes, from the healthcare provider's perspective. As a result, women felt that they were being encouraged to expect these reassuring (and best) outcomes. Meanwhile, women wondered how these best outcomes could be achieved by most women; yet they did not know how to have a discussion about poor outcomes with healthcare providers, particularly when women perceived these providers to be hardworking experts who had the best intentions.

In particular, women questioned their healthcare providers' reassuring descriptions of the physical outcomes of surgery, as well as the expected feelings of wellbeing during and after chemotherapy, radiation therapy, and hormone therapy. For example, in speaking about autologous breast reconstruction, one woman said that the surgeon was "enthusiastic" about the "tummy tuck" she would receive during the surgery. The implication being, "we're (surgeons are) gonna make you better than you were before," and her physical body would be improved after breast cancer. This same woman was pleased with her surgery outcome, however, she was ambivalent toward the surgeon's approach. In her view, the surgeon glossed over potential problems. She commented:

> “I think you actually set yourself up for a little bit of failure and a little disappointment on our side, in your [the surgeon’s] enthusiasm. I would have preferred, you know, ‘this is what we have to offer you, and we’ve come a long way, and it’s gonna be way better than nothing at all, but it’s not pleasant’… I can’t believe that [the surgeon] hasn’t set more women up for failing. That they didn’t quite… that this whole thing didn’t live up to what [the surgeon had] said it was gonna be.” (Participant 7, age 55)

This way of conveying treatment information was not unique to surgical outcomes, it was also used in providing information for other treatment modalities as well. For example, a young woman described the information she received from her healthcare provider about chemotherapy. She said:

> “It [chemotherapy] was kind of framed as in… you know this is cancer, you will have all this treatment but, ‘You should be fine. Some people bike in to get their chemo’… except I didn’t bike in to get my chemo. So it was framed very positively.” (Participant 1, age 35)

The reassurance – that she would feel well enough to cycle during chemotherapy – was unrealistic in this woman’s view. Further, this attempt at reassurance precipitated this woman’s feeling that her provider did not make care personal to her, and her personal worries and priorities were disregarded.

Women wanted conversations with their healthcare providers about what they could expect from different treatments, including typical and poor outcomes. Women wanted to talk with providers about what they hoped for in the physical and functional aspects of their bodies after treatment. Without conversations about treatment outcomes that are personal, it was difficult for women – who may already be struggling to determine their priorities in a new and uncertain situation – to access the information that would enable them to make decisions that were consistent with their wishes.

Finally, providing information to women about cancer and its treatment was difficult when women perceived their healthcare providers to be lacking in empathy. In particular, women expected that their healthcare providers would make available the time required to satisfy their information needs, and they also hoped to be comforted by small actions. It appeared that information provision was well received by women when they perceived empathy.

From the descriptions of women, the amount of time a healthcare provider dedicated to appointments varied, and yet providers were able to convey empathy in both shorter and longer appointments. Women were also pleased when healthcare providers offered women the opportunity to formulate more questions for a later time. One woman said that her surgeon explained treatment options and then asked her if she had any questions. When she was not sure if she had more questions, the surgeon offered that they could have another discussion if needed before she decided on surgery. The woman said, "I do believe you do have that time to make the decision [then you think]… I did get scared because I really could feel it growing and I wanted it out of me… [but] we have more time than we realize" (Participant 7, age 55 years).

Also, small actions, such as comforting touch, were perceived as signs of empathy by women. Touch provided a sense of calm and reassurance in difficult appointments. A 56 year old said of her oncologist, "She gave me the time of day, she wasn't rushed to go to her next patient. You know, she was comforting, like she even touched you. Like to reassure you" (Participant 10). In this example, the woman relayed that her healthcare provider took *time* in the appointment, yet *touch* was also a cue for empathy. In another case, an older woman described her experience of needing comforting touch at the time of diagnosis and treatment discussion. She said:

> "If someone maybe would just put their hand on my shoulder. And I understand they can't give hope, when they don't know hope is there. I understand all that, but I think just maybe put your hand up on their shoulder, because every time I walked out of the office I thought for a while I was gonna die." (Participant 13, age 74 years)

This woman, and others like her, needed calming actions to help when emotional distress is high. Attending to time and touch are small, but important, ways that healthcare providers created environments where women could attend well to cancer and treatment information.

Barrier 5: Access to Information

Women believed that basic information and specialized services were available to them, but some women did not know what to ask or who to approach for the information. Here, basic information refers to information that assists women in understanding their cancer diagnoses, as well as information to develop an understanding about benefits and risks associated with various treatments. Information about specialized services refers to information about services which are not provided by the healthcare provider directly, yet are important to women in their care. These services may be provided within the healthcare organization (e.g. nutrition counseling, support groups, a second opinion) or they might be external to the healthcare organization (e.g. fertility preservation, genomic testing, custom breast form, a second opinion). Thus, at times, access to basic information and information about specialized services was facilitated by the healthcare providers or the healthcare organization and, at other times, accessing this information was the responsibility of the diagnosed woman.

All women in this study wanted to understand basic information about their cancers and treatment options, but – as referred to earlier – some women struggled to formulate questions within the timeframe of the consultation appointment. One woman said that she felt confused about her diagnosis, but did not know what to ask: "They said, 'do you have any questions?' I don't know what I'm talking about, how can I ask questions?" (Participant 13, age 74). This woman left her appointment having made a treatment decision, but she said that she did not understand her choice.

Many women needed guidance in formulating questions about basic cancer and treatment information, so that they could understand more about their diseases and the treatments offered. Yet, even when women formulated specific questions, they often did not know who to ask outside of their consultation appointment. Most women had the contact information for a nurse, but were reluctant to go to the same nurse with all of their questions – either because women did not want to burden the nurse, or because the women felt the questions were not directly connected to the care provided by the nurse. For example, a 40 year old woman had questions about treatment side effects, exercise and nutrition. She explained, "I had lots of questions. So every time I had a question… I had no idea who I was supposed to call" (Participant 20). Accessing basic information was difficult for women with breast cancer.

As well, women struggled to access information about services that they believed were available to them as women newly diagnosed with breast cancer. In this local context, some services, such as breast reconstruction, were readily available and access was facilitated by healthcare providers. Other services were not accessed through healthcare providers. Women of all ages described the challenges associated with accessing information about other services, particularly genomic testing and second opinions. In particular, however, the younger women of childbearing age described the added strain associated with accessing fertility preservation services. These women worked to understand the effects of breast cancer on fertility, worked to understand what fertility preservation entails, and then worked to find out if fertility preservation services were available to them. One woman described her struggle to get information about fertility preservation prior to her breast cancer treatment. She stated:

> “I met the biopsy person and then I met the surgeon and then I was supposed to have surgery. When were you guys gonna talk to me about fertility? Who was gonna talk to me about it? Nobody made it clear about, you know, you call this one central person and they help you with all kinds of stuff. [Instead] it’s like, ‘okay surgery’s next.’ And all the questions I had in between, I had no idea who I was supposed to ask.” (Participant 20, age 40)

These women described the anguish involved with facing the reality that they may experience infertility due to cancer. It was an added burden for a woman to be responsible to access information about the effects of treatment on fertility, what services were available, and to determine if the cost and timing of fertility preservation was feasible before she underwent her primary treatment.

Lifespan Considerations

The five barriers to information support presented here were the same for women regardless of age. These barriers were consistent across the lifespan groups studied here, and women of every age wanted information support during the treatment decision making experience. In regard to access to information, a difference was noted in younger women required access to fertility preservation information.

However, notably, all women were concerned with information pertaining to symptom management, partly due to concerns about their abilities to continue to engage in activities of caring during and after treatment. These caring activities related to mothering (young children, adolescents, adult children and grandchildren), as well as caring for aging spouses or close friends. In general, women at every age wanted to manage their symptoms so that they could continue to participate in the lives of their loved ones. A 58 year old woman explained that she wanted information to manage her symptoms because:

> "It's all about me and having a, planning a, like, a good future for – like to be healthy for my family and, well, for myself. Because… if I'm not healthy, how can I be fun with my family right? I love playing with my grandkids and doing stuff with them and… all my plans is, well pretty much all around family." (Participant 9)

Discussion

This study described the patient perspective regarding the barriers to information support in breast cancer treatment decision making. In particular, women described their experiences regarding heightened emotional distress, patient-provider communication, provider-provider communication, making treatment information personal, and difficulty in accessing information.

Emotional Distress

The emotional distress involved in the experience of breast cancer was well documented (Epping-Jordan et al., 1999; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001) and it has been thought that younger women were at more psychosocial risk than older women in breast cancer at the time of diagnosis (Compas et al., 1999; Epping-Jordan et al., 1999). However, in this study, women of all ages cited the interference of shock and fear on attending to information soon after diagnosis. Where the relationship between patient cognition and psychosocial symptoms have been explored, cognitive dysfunction has been assessed both via “subjective” means (patient reported) and “objective” means (neuropsychological testing). There is a lack of relationship between subjective and objective cognitive dysfunction in breast cancer (Pullens, De Vries, & Roukema, 2010), suggesting that subjective levels of cognitive impairment occur pre-treatment and is associated with anxiety, depression and severe fatigue rather than the effects of treatment (Ahles et al., 2008; Sarason, 1984; Servaes, Verhagen, & Bleijenberg, 2002).

Women in this present study revealed that women of all ages experienced a level of emotional distress which, even when appearing as typical for this context, may interfere with processing cancer information (Erblich, Montgomery, Valdimarsdottir, Cloitre, & Bovbjerg, 2003). When information is provided without checking what the patient has retained (Politi & Street, 2011), women may be unprepared to make satisfying treatment decisions. This is significant because barriers to the provision of healthcare are thought to exist at various levels, including the patient-provider level, the provider-provider level, within the healthcare organization, and external to the delivery of care

(Adler & Page, 2008). The results of this current study point to an additional level, that being at the level of the individual patient. In this study, the overwhelming emotion of the individual due to the cancer experience was a barrier – not only a barrier of provision of information, but a barrier to the ability of the patient to process information due to emotional distress. While problems at the other levels can be addressed, those solutions may have little impact without addressing the emotional needs of patients, so that patients can attend to the information being provided.

Patient-Provider Communication

Since the use of medical jargon impedes patient understanding and contributes to poor cancer communication, it has been recommended that healthcare providers use plain language in cancer (Fagerlin, Zikmund-Fisher, & Ubel, 2011). Despite these recommendations, the use of medical jargon continues to be problematic. These problems occur at the patient-provider level, but may also be due to systemic misunderstandings. These systemic misunderstandings are generally accepted practices by the healthcare organization, or system, that create unintended harm to patients due to assumptive gaps between providers and patients (Thorne et al., 2013). These systemic problems not only affect the individual patient, but the larger patient population as well.

Further, women in this study described the omission of treatment information during consultation appointments. It is unknown if women were provided information and were unable to attend to it, or if the information was not provided at all. If information was omitted entirely, this may be due to paternalistic models of care, such as benevolent paternalism, where healthcare providers only offer choices that the provider feels is in the best interests of the patient. However, even when they provide, or intend to provide, all the information patients need or request, the timing and method of delivery of information is debated (D’haese et al., 2000; Waller, Forshaw, Bryant, & Mair, 2014). Nonetheless, the omission of treatment information – whether or not this information was intentionally delayed or unintentionally omitted – lead to confusion and frustration for newly diagnosed women in this study.

Provider-Provider Communication

Issues of inconsistent messaging and occasions when patients felt caught between the opinions of their healthcare providers, point to a lack of coordination of care. While not cancer specific, coordinated care in inpatient units is associated with higher patient satisfaction and lower morbidity and mortality (Knaus, Draper, Wagner, & Zimmerman, 1986; Young et al., 1998); better coordinated care in outpatient facilities is associated with higher perceived health status and an increase in adoption of preventive services by individuals (Flocke, Stange, & Zyzanski, 1998; Safran et al., 1998). There is reason to consider that better coordinated care may increase patient satisfaction and optimal health outcomes in the context of breast cancer treatment.

One study looking at continuity of care for patients, showed that a barrier to coordinated care was the “ineffective team” – or a team which included a failure to recognize the roles and responsibilities of multiple healthcare providers (Walsh et al., 2010). The findings of this present study agree that the lack of communication between providers may produce ineffective teams. In the view of these patients, healthcare providers did not describe or interpret their roles to the patient, nor did healthcare providers they demonstrate their responsibilities in coordinating information with each other as care providers.

Making It Personal

In this study, the provision of information support was hampered when healthcare providers made treatment discussions too personal by using persuasive language to convey treatment information. By using emotional language, the women in this study shifted the focus from sharing their own information with their providers, and attending to their own personal worries and wishes, toward the perceived needs of their healthcare providers. Dunn and Steginga (2000) report a similar phenomenon – they concluded that younger women's breast cancer treatment decision making process was confounded by emotive messages in the media about breast cancer expectations and stereotypes (Dunn & Steginga, 2000). Where Dunn and Steginga (2000) look at emotive messages through the media, the results of this present study point toward a potential similar confounding of the decision making process by emotive messaging from healthcare providers.

At other times, patients felt that interactions with healthcare providers was not personal enough – patients were overly reassured about treatment outcomes or they felt a lack of empathy from their healthcare provider. When healthcare providers did not provide a balance of treatment information, or were overly reassuring about specific aspects of treatment, women focused on better outcomes of treatments and they wondered if their healthcare providers understood what was important to them. Keeping in mind that this is in the context of discussing curative treatment choices, and discussing palliative care options may have different challenges (Schofield, Carey, Love, Nehill, & Wein, 2006). However, even in the context of curative treatment, where prognosis may be very good, the motivations for healthcare providers to choose this method of conveying information is unknown.

It is also known that providing empathy in the patient-provider encounter is beneficial (van Vliet & Epstein, 2014) and does not need to prolong patient visits (Morse, Edwardsen, & Gordon, 2008). This present study highlights that some women perceived empathy through touch and/or time. However, there may be cultural aspects to perceived empathy that must be considered (Fujimori et al., 2005; Surbone, 2006), such as when touch or eye contact is not desired. As a result, it is all the more important that these interactions be personalized to the needs of the patient.

Access to Information

Where it is thought that older women may not ask or formulate questions about treatment as readily as younger patients (Husain, Collins, Reed, & Wyld, 2008), younger and middle aged women in this study struggled with formulating questions in the same way as the older women did. Prior research shows that not all patients want further information about cancer than what is provided by their healthcare providers (Leydon et al., 2000), but information needs change over time and patients must be consulted regularly about their current information needs (Butow, Maclean, Dunn, Tattersall, & Boyer, 1997).

Also, whereas existing studies suggest that younger patients seek more information than older patients (Galloway et al., 1997; Jenkins, Fallowfield, & Saul, 2001), all women in this study sample wanted to be provided with information about general cancer information as well as specific treatment information. Accessing information was an obvious frustration for women of all ages, particularly for women who wished to obtain information about specialized services. They wondered if their healthcare providers were the gatekeepers of these services (Bombard et al., 2014) or if all women were responsible to access these services on their own.

In particular, younger women had a great need for fertility preservation information and, as this study illustrates, did not receive access to information in a timely way. This agrees with other research stating that young patients do not receive sufficient information about the impact of cancer treatment on fertility (Avis, Crawford, & Manuel, 2004; Partridge et al., 2004; Peate et al., 2011), yet concerns regarding infertility impacts treatment decisions for many young women with breast cancer (Partridge et al., 2004; Peate et al., 2011). The experience of several women in this study was that the provision of this information did not occur at all and healthcare providers did not perceive it to be their responsibility to facilitate access to this information. Why this occurred is unknown, yet it may also be the case that healthcare providers experience discomfort in discussing fertility preservation (Quinn et al., 2009), preventing the information from being provided.

Implications for Research

Whereas distress has been recognized as the 6th vital sign in cancer care (Bultz & Carlson, 2005; Holland & Bultz, 2007), leading to programmatic screening for distress in many cancer centres (Bultz et al., 2011), these findings support a continued need to screen for distress; including the screening of patients as soon as possible in the cancer experience, rather than beginning screening while in chemotherapy and radiation therapy. One of the goals of screening for distress has been to identify distress so that the psychosocial needs of the patient may be met at the right time. The results of this study point to screening patients early after diagnosis in order to support the decision making experience. By better attending to distress early on, women may better be able to recognize their personal priorities. Also, by attending to distress earlier, communication problems between patients and providers may be better mitigated as well. As a result, this study supports the further investigation of the impact of emotional distress on the experience of breast cancer prior to treatment. Strategies to create environments where patients can better process information must be examined. One such environment may be a trauma-informed, or trauma-sensitive, context. Trauma-informed care may have a place in cancer care since it has been recognized that the diagnosis of a life-threatening illness is a potential trauma (Mehnert & Koch, 2007). A higher rate of post-traumatic stress disorder (PTSD) is found among cancer patients than in the community (Alter et al., 1996), occurring in 3% to 4% of newly diagnosed patients. In breast cancer, studies have shown the prevalence of PTSD to range from 2.4% to 19% of the diagnosed population (Koutrouli, Anagnostopoulos, & Potamianos, 2012), and the incidence of post-traumatic symptoms without a full PTSD diagnosis is higher (National Cancer Institute, 2015).

However, even when trauma is not measured subjectively, the unexpected nature of a cancer diagnosis is a stressful event that many leave the patient feeling unprepared and out of control. This lack of preparation and control in the highly stressful situation of illness may be defined as traumatic, even when a person has not been traumatized in the past (Klinic Community Health Centre, 2013). As a result, negative effects may occur, including decreasing a patient’s ability to understand and retain information needed, or changing the patient’s ability to react to information. Whereas unprocessed trauma creates disconnection (Marich, 2014) and powerlessness (Harms, 2015), care that is sensitive to trauma can be provided at the individual, organizational and systemic levels (Greaves & Poole, 2012). This care works to create spaces, programs and policies that provide an acknowledgement of stress, as well as the need for safety, trust, collaboration, choice and control for patients (Evans & Coccoma, 2014; Greaves & Poole, 2012). Integrating a model of care, which incorporates trauma-informed practices, may help support women as they work to integrate their experiences of cancer diagnosis and treatment into their lives.

Finally, women in this study demonstrated that healthcare providers' use of emotional language was prevented women from learning more about their cancer and treatment options. This is a unique finding which provides a starting point for research in this area. Further research must be developed to determine how women understand (over)personalized statements by healthcare providers, and how these statements may influence treatment decisions.

Implications for Training and Practice

These findings indicate communication problems at the patient-provider level which may be addressed using multiple approaches, the first of which is continued and improved communication training for healthcare providers. Although results appear to be inconclusive as to whether or not communication training reduces patient distress and increases patient satisfaction (Uitterhoeve, Bensing, Grol, Demulder, & Van Achterberg, 2010), there is growing evidence that targeted training improves basic communication skills (Gysels, Richardson, & Higginson, 2004). Continued development of communication training methods and content is required to understand the role of education in communication skill growth for healthcare providers.

Also, these findings show the difficulty in information provision due to provider-provider communication problems. The implementation and expansion of interprofessional care models – such as healthcare team models or communities of care (Haidet, Fecile, West, & Teal, 2009) –may provide patients with continuity of care, and the connectedness they desire with their healthcare providers. These collaborative care models have the potential to ameliorate the effects of poor patient-provider communication (Thorne et al., 2013), alleviate disconnection between healthcare providers, and promote the patient's place in the healthcare team by placing the patient's needs at the centre of care throughout the cancer experience.

Limitations

This study has limitations in that the results describe the experiences of women living with breast cancer in one Canadian province, and may be a reflection of the local healthcare organizations and the provincial healthcare system. Although women of different cultures and ages contributed to the findings, women living in other geographical regions may experience different barriers to breast cancer treatment information support. Further, the stage that breast cancer is diagnosed may influence the information that women seek. Whereas most women in this sample were diagnosed with Stage I-III breast cancer and were offered curative treatment options, women with advanced cancer may experience different barriers to treatment information support. Finally, this study sought to contribute to understanding how age may influence the decision making experience, but not other demographic factors. Further research with non-English speaking women, women of a variety of cultural backgrounds, and rural women is needed to explore what information support is needed in other contexts.

Conclusion

When diagnosed with breast cancer, women of all ages desire information about their cancer and its treatment. This study highlights five barriers to information support, with barriers occurring at various levels, including the level of the individual patient. Further investigation is needed to understand how reducing emotional distress may influence decision making prior to treatment, how communication skills training can enhance the experience of patients as they undergo the decision making process and how the implementation of interprofessional models of care may better enable the provision of information support for women with breast cancer. Addressing these needs may empower women with breast cancer to make satisfying treatment decisions that are sensitive to their individual healthcare needs and wishes.

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CHAPTER 7: DISCUSSION AND CONCLUSION

This chapter presents a summary of the overall findings of the study, discussion of these findings, as well as a presentation of overall recommendations for future education and practice, research, and policy considerations. Also included are descriptions of knowledge translation activities and overall study limitations.

The Overall Findings

The overall purpose of this qualitative, grounded theory study was to explore the decision making experience in the early cancer journey for women with breast cancer of various ages. Methods of data collection included demographic surveys, field notes and semi-structured interviews with 22 women diagnosed with breast cancer. In all, 29 interviews were conducted with women ranging from 32 to 80 years of age.

Summary of the Findings

Women encountered the problem of not understanding cancer and its treatment, yet they needed to make treatment decisions. This problem was met by a process of learning about cancer and its treatment. A model depicting this process, *the ways of learning in breast cancer*, was presented in chapter five. The model includes the beliefs, values, and actions of women. Also, two ways of learning were presented, women with breast cancer learned about cancer and its treatment by trusting the healthcare system and/or trusting a system of connections. Women of all ages utilized these two ways of learning, yet younger women indicated that they learned by trusting a system of connections more often than older women.

These ways of learning are consistent with existing theory stating that beliefs, values and attitudes guide actions (Ajzen, 1985; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975), that women learn through connectedness and relationships (Belenky, 1986; Flannery, 2000), and that humans learn incidentally and within informal contexts (Watkins & Marsick, 1992). This study adds to existing knowledge by highlighting incidental learning occurs in the absence of nonformal education activities in the context of cancer, and that there are different ways of learning in this context. This study also describes the specific beliefs that patients may hold about authoritative knowledge in healthcare, and the influence these beliefs have on the ways that patients learn about illness and its treatments. Further, the patient's age, or cohort, may influence the way in which they learn in this context, however women have the capacity to shift between ways of learning as they navigate treatment decision making experiences over time.

Also, as presented in chapter six, findings revealed that women of all ages desired information in breast cancer, yet many experienced barriers to information support when making treatment decisions. In this study, barriers to information support included the emotional distress experienced by the diagnosed woman, patient-provider communication problems, provider-provider communication problems, providers making information too personal or, at times, not personal enough, and difficulties in accessing information.

Several barriers presented here have been discussed in prior research. For example, it has been previously shown that women experience emotional distress at diagnosis (Zabora et al., 2001) which can interfere with the processing of cancer information (Erblich, Montgomery, Valdimarsdottir, Cloitre, & Bovbjerg, 2003). This study adds to this knowledge by showing that women of all ages experience this phenomenon. While it has been thought that barriers to healthcare exist at the patient-provider, the provider-provider, within the healthcare organization, and external to the delivery of care (N.E. Adler & Page, 2008), other literature has not highlighted the barrier to information provision that occurs that the level of the patient when the patient experiences emotional distress at the point of treatment decision making.

Communication barriers have been presented elsewhere, including patient-provider communication problems (S. Thorne et al., 2013) and provider-provider communication (Knaus, Draper, Wagner, & Zimmerman, 1986). This present study describes the experience of women when treatment information was omitted during consultation appointments, leading to frustration and confusion for women. Women also described confusion when providers were not clearly communicating with each other, particularly when providers disagreed with a specific diagnosis, treatment regimen, or patient's prognosis.

This study showed that women struggled with the treatment decision making experience when healthcare providers presented treatment options using emotional language. In these cases, women shifted their focus from considering how they are feel or think about the treatment option, toward perceiving the needs of their healthcare providers. This phenomenon has not been studied widely, although there is research showing that cancer treatment decision making process can be confounded by emotive messages in the media about expectations and stereotypes in breast cancer (Dunn & Steginga, 2000).

Finally, women of all ages struggled to formulate questions about cancer and its treatment. This is different from research that focuses on older women's difficulties in asking questions of their healthcare providers (Husain, Collins, Reed, & Wyld, 2008). Accessing information was a struggle for women of all ages, but more even more difficult when women desired information about specialized services, such as fertility preservation.

Discussion of the Findings

This section integrates the findings by discussing how chapters five and six relate to each other. A discussion of specific aspects of the research questions follows.

Integrating the findings. The most substantive section of findings were presented in two separate manuscripts, yet these findings integrate with one another when describing the experience of treatment decision making in breast cancer. All findings represent the patients' needs and desires for information, as well as the provision of timely and appropriate information about cancer and its treatment.

In this study, the patients faced the problem of needing to make treatment decisions while not fully understanding cancer and its treatments. The process that patients utilized in solving this problem, was to learn while navigating the experience of breast cancer. This learning was incidental in nature. Other decision making research focuses on providing patients information through clarification of specific patient information needs (Feldman-Stewart, Madarnas, et al., 2013) and values (Fagerlin et al., 2013; Pieterse, de Vries, Kunneman, Stiggelbout, & Feldman-Stewart, 2013), developing better understandings of patient coping (Witt, Elwyn, Wood, & Brain, 2012), testing interventions to support the better provision of information (Elwyn, Stiel, Durand, & Boivin, 2011; Feldman-Stewart, O'Brien, et al., 2013), and improved communication between patients and their providers (Brundage, Feldman-Stewart, & Tishelman, 2010). This research is of the utmost importance, and current research in this area continues to develop.

Considering how patients learn in the context of illness is a similar, but slightly different concept than information needs or support; patient learning focuses on the processes patients use to gain the information they desire, and what will be helpful to them as individuals in decision making, as opposed to the provision of specific information through interventions. When we better understand how patients go about learning, we may better understand information support in this context.

At this time, there is no other known research to describe the processes patients use to learn in the context of cancer. As a result, these study findings are a step toward an overall understanding of treatment decision making from the patient perspective – when we better understand information support in treatment decision making, and we better understand how patients go about learning about cancer and its treatment, a better overall understanding of the experience of decision making may be reached. Accordingly, this study contributes to the theoretical gap between what we know about specific information needs in cancer and designing specific interventions (Elwyn et al., 2011) to promote learning about cancer and its treatment. Appropriate decision making interventions can be developed as a result of further research in this area.

Consistent with known learning theory (Bandura, 1986), we posit that, when patients learn, they self-regulate or control (consciously or unconsciously) what and how much they learn at a given time. However, without learning opportunities, patients lose control over some of this learning. What the healthcare system and the community can contribute, are added learning opportunities that are consistent with various ways of learning. That is, the healthcare system can alleviate barriers to information support by adding opportunities to learn within consultation appointments, outside of formal appointments, and by acknowledging to patients that helpful learning opportunities exist outside of the healthcare organization or system. Permitting patients to reflect on their learning (Schön, 1983) may further increase their learning about cancer and its treatment, thereby supporting patients in their treatment decision making.

The research questions. The research questions were answered in chapter four, yet a brief discussion occurs below. Research questions address meanings women assigned to decisions, the psychosocial factors involved in treatment decision making, and changes across the lifespan in treatment decision making.

Meanings assigned to decisions. Humans tend to look for meaning in suffering (Frankl, 2006). At a diagnosis of a life-threatening illness, such as cancer, patients may interpret the diagnosis as a traumatic event, bringing questions about why they were diagnosed and what it might mean for their future (Jim, Richardson, Golden-Kreutz, & Andersen, 2006). Research suggests that meaning making is multidimensional and may be comprised of the networks in the life of the patient (Weisman & Worden, 1976), as well as the value a patient assigns to her life (Hutzell, 1986). Further, it is thought to be beneficial for women with breast cancer to accept and acknowledge meanings made (Collie & Long, 2005), as long as these meanings are valuable to women themselves and are supported, even when they are counter to or resist the structures and powers that exist at a given time (Collie & Long, 2005). Consistent with this research, the participants in this study assigned their own meanings to cancer as well as to decisions faced in breast cancer.

In this study, women approached decisions with specific meanings in mind. Also, a pattern of women looking to information to either confirm positive meanings or oppose negative meanings was shown. At times, women looked to information to support the positive meanings they made of cancer and treatments; at other times, women looked to information to negate meanings that were negative, thereby potentially altering their opinion of specific treatment options. However, this study was not able to determine whether or not women changed the meanings of treatment decisions as they learned about cancer and its treatment.

Differentiation and Consolidation Theory (Svenson, 1992) is a descriptive decision making theory relating to this phenomenon. This theory argues that decision makers deliberate a problem, prior to decision making, by differentiating one alternative from others, repeating this process, until there is enough of a difference between alternatives to make a decision. A superior option must exist in order to make a decision in this way. After the decision is made, decision makers use consolidation, a process of restructuring thoughts to guard themselves from future doubt about decisions already made. In essence, consolidation is effort that prevents decision makers from feelings of regret or cognitive dissonance after a decision is made (Elwyn et al., 2011). In this study, there was no evidence that women undertook deliberative strategies as described by Svenson (1992). In fact, women described that the emotional distress of diagnosis, and the limited time they felt they had to make decisions, interfered with any structured deliberative processes. However, women did look to information that would consolidate decisions made, perhaps as a strategy for coping with the decision making experience.

Psychosocial factors influencing decision making. As noted at other points in this thesis, emotional distress is often present for women newly diagnosed with breast cancer (Epping-Jordan et al., 1999) and influenced the decision making experience for women in this study. Other research has shown that psychological factors impact information needs and decision making in cancer. For example, a study of men with prostate cancer (Wong et al., 2000), showed that men with increased optimism wanted detailed treatment and men with lower mood wanted information about psychological support. As a result, it may be important to consider patient optimism and/or mood in further research about learning and information support in breast cancer treatment decision making.

Other psychosocial factors influenced decision making as well, including social support. Women in this study explained that loved ones were present in treatment decision making discussions, but did not impact women's choices. While sometimes women did not feel that they had much choice in having treatment or not, based on a desire to survive without recurrence, women did not appear to share the responsibility of treatment decision making. This was seen in earlier research about mothers with cancer (Campbell-Enns & Woodgate, 2013), however other research shows that the involvement of spouses, family members and other companions can vary depending on cultural practices (Mead et al., 2013); demonstrating that women of varying cultures do not identify their loved ones as being the final treatment decision maker, such as African American and Caucasian women in the United States (Hawley et al., 2009). Regardless of the role that spouses may play in final treatment decisions, women with breast cancer have shown that they believe that spouses play a significant role and spousal agreement with decisions made is important (Gilbar & Gilbar, 2009).

Finally, quality of life aspects of cancer influenced treatment decision making in this study. While other research in this area is concerned with how participation in decision making impacts quality of life of patients (M. R. Andersen, Bowen, Morea, Stein, & Baker, 2009; Thomas F. Hack et al., 2010), this study highlighted the reverse – that quality of life may influence decision making. This study showed that poor quality of life during cancer both deterred women from eliciting information and, at times, spurred women on to expand their systems of connections. It is unknown why these different responses resulted. However, when women felt ill due to a previous treatment, they either continued to trust their healthcare provider, therefore taking a more passive role in the next decision, or they were spurred on to increase learning opportunities because they lost confidence in their healthcare provider's judgment, or they needed to increase their confidence in their own judgment (Henderson, 2003).

Lifespan changes in decision making. Difference were noted between the decision making experience of younger and older women. First, younger women in this study faced an increased number of decisions in comparison to the older group of women, much like previous research showing that younger and older women are not treated to the same extent (Allemani et al., 2010; Markopoulos & van de Water, 2012; Yancik et al., 2001). To understand these differences, further research would need to be conducted to include access to patient records and/or interviews with healthcare providers.

Also, women of different ages trusted a system of connections in decision making, yet the younger group did so more often than the middle aged or older groups. Further, the younger group was more apt to shift their way of learning about breast cancer from trusting the healthcare system to trusting a system of connections for later treatment decisions. This difference may represent the possible difficulty older women had accessing a network of connections in breast cancer (Yoo, Levine, Aviv, Ewing, & Au, 2010). The result being that older women may need to have assistance in learning to reach out to others and create larger networks of support for treatment decision making.

Another explanation is that older women from this cohort may have been more likely to hold the belief that the healthcare system has authoritative cancer knowledge, whereas the younger cohort in this study was more interested in having a personal knowledge of their specific diagnosis. Authoritative knowledge is one type of knowledge and has been applied to early breast cancer research, showing that the most common sources of authoritative knowledge are healthcare providers, healthcare decision aids, and patient education materials (Warren, Mendlinger, Corso, & Greenberg, 2012). The present study expands the concept of authoritative knowledge to include knowledge sources outside of the healthcare system. Also, authoritative knowledge research has not examined age differences; women in this study showed changes across the lifespan, yet results are limited by the sample size and conclusions cannot be drawn as to the reasons for these age differences in women's ways of learning.

Recommendations for Education and Practice

Findings regarding ways of learning and barriers to information support suggest that, in order to empower patients to learn cancer information, healthcare providers must attend to the emotional distress at diagnosis. As a result, screening of distress and/or conversations about the distress brought upon by a diagnosis, should occur early in the cancer experience, rather than waiting to evaluate and treat distress until after treatment begins. In conjunction with these practices, education opportunities must be provided to clinical staff in cancer care settings to better understand how emotional distress may impact how patients receive and use cancer and treatment information.

Second, those working within the healthcare system should recognize the learning that occurs in the early days of a cancer diagnosis, particularly, when patients are making treatment decisions. This learning may be incidental, but an awareness of the learning that is occurring may engage healthcare providers to attend to better information support in this highly complicated context. Attending to learning needs may result in mitigating barriers to information support.

Third, utilizing interprofessional models of care is recommended to provide better continuity of care, and to place the diagnosed woman at the centre of her care. Within an interprofessional model, healthcare providers collaborate and share information with each other and the patient, as well as coordinate care processes. Also, where women were dissatisfied with patient-provider communication, and provider-provider communication, these models of care may ameliorate the effects of poor communication and increase the ability for providers to communicate with each other. Further, whether or not interprofessional models of care are formalized, it is recommended that healthcare providers communicate with patients in a fashion that encourages patients to explore learning about their cancer and their treatment options both within, and external to, the healthcare system.

Recommendations for Research

A model of *ways of learning in breast cancer* was created from these findings; building on this model has the potential to create a theoretical understanding of learning in illness, a concept to complement current research on the provision of information in cancer. Fundamental knowledge about ways women learn in breast cancer has been presented here, with the hope of encouraging further research on the learning that occurs in this context.

Also, expanding this study to other geographical regions may indicate different ways of learning in breast cancer and different barriers to information support. Other design changes would be welcome as well so that other points of diversity would be emphasized (e.g. first languages, culture, rural women, single women, women with advanced cancer); research among other populations may lead to gaining a better understanding about how women learn in the context of breast cancer, and what information barriers are faced by diverse groups of women with cancer.

While women in this study were all recruited within the healthcare system, future opportunities must seek to recruit women who have decided to receive cancer care external to the traditional healthcare system, or no formal care at all. If this were to occur, there is the potential to expand the typology of ways of learning, as well as better understand the barriers to information support in these contexts. As a result, it is important to engage patients in research who are not working within the traditional avenues of cancer care while making treatment decisions.

Findings suggest that further research be undertaken to investigate the impact of distress prior to cancer treatment. Whereas the experience of a new cancer diagnosis may be traumatic for an individual, the use of the trauma-informed care practices may provide increased feelings of safe physical spaces and safe interpersonal processes for patients with cancer. Thus, conducting research using a framework that includes the principles of trauma-informed care may be useful; this research is required to better understand if increasing patient’s felt safety assists patients in making more satisfying treatment decisions.

Recommendations for Policy

Study findings provide policy direction for local and provincial levels. First, the composition of the care team, and defining the roles of team members, is a policy matter. Participants in this study experienced communication problems that could be alleviated by the implementation of interprofessional care models; these models of care have the potential to increase strategies to provide information to patients, supporting ways of learning in breast cancer. Models of care are continually changing in Manitoba, and incorporating interprofessional care models in breast cancer can occur via current quality improvement strategies. As measures of quality improvement study and test the value of an interprofessional model of care, appropriate changes in policy can be made.

Also, persons with cancer in Manitoba are screened for their distress at most clinic visits, yet not usually prior to a treatment decision making has begun. Emotional distress is gauged by a screening for distress tool, which is part of the provincial cancer agency's standards of care. The process of implementing the screening tool has been ongoing since 2011, with great success. However, there are known logistical difficulties in screening patients when making first treatment decisions because most screening tools are for cancer populations; difficulties include the danger of asking patients about distress before they have been presented with a diagnosis, as well as screening patients in clinics where patients with and without cancer are both seen by clinicians. However, study findings suggest that women with breast cancer need to have emotional distress addressed when receiving information about first treatment decisions. Developing new clinical processes around implementing a screening tool for newly diagnosed patients is an important step in recognizing the emotional distress of patients facing treatment decision making. A pilot project in a breast cancer clinic could lead to practice and policy change in this area.

Lastly, policy changes are required to provide better access to information for women with breast cancer. Findings showed that women experienced uneven information about breast reconstruction options, in particular women did not receive satisfying and timely information about breast prostheses, or what it might be like to forgo breast reconstruction. When women considered breast prostheses, they were surprised that a high quality prosthesis was not fully funded, whereas surgical breast reconstruction was funded in full. Other findings showed that women did not receive satisfying and timely information about fertility preservation and, women found the costs of fertility preservation to be prohibitive. Another service which lacked information was genomic testing prior to chemotherapy. Many women did not know about genomic testing until after they had started chemotherapy; other women had heard of the testing but did not know if it was appropriate for them, or they found the cost prohibitive. The lack of information about these services may indicate that these services were not provided within the healthcare system. Nonetheless, women need to have timely information about these services and all women should be provided this information.

As a result, partnerships between cancer care centres and other centres providing services (i.e. prostheses providers, fertility centres, genomic testing centres) must be strengthened and formalized. Further, equal access to these services may only come for women across the province when policy is developed, therefore new standards must be set to include improved information and funding for all women who are considering prostheses after mastectomy, genomic testing prior to chemotherapy when appropriate, and fertility preservation for all pre-menopausal women with a new diagnosis. A province-wide adoption of standards that include information on these services is necessary to meet the needs of this group.

Knowledge Translation

Findings will be disseminated to researchers and clinicians through published papers in peer-reviewed journals, as well as presentations at conferences and cancer centres. It is expected that findings will be aimed at health care professionals and researchers at this time, further research is needed prior to creating materials for patient learning.

Knowledge Translations (KT) activities will be tailored to researchers and clinicians through peer-reviewed publications. Chapters five and six will be submitted separately for publishing in journals which focus on patient decision making and/or psychosocial oncology. Beyond publications, a report providing a summary of the study findings and recommendations will be submitted to the provincial healthcare organization, as well as the local breast health centre. Also, a brief report summarizing chapter six findings was provided to study participants.

Presenting findings at conferences will be an important KT strategy. The preliminary results regarding the barriers to information support were presented at one international conference in July, 2015. Abstracts for these findings, as well as findings about learning in cancer, will be submitted to be presented at conference proceedings in 2016. Local opportunities to present findings will be sought at the provincial cancer agency and at the University of Manitoba.

Study Limitations

The findings of this study have limitations. First, this study was conducted in one Canadian jurisdiction, and reflects the experience of the women diagnosed with breast cancer in this geographical area. These findings also reflect the local healthcare practices and the provincial healthcare system(s) involved in the care of these women. Interviewing women in other health jurisdictions may garner novel responses. Also, all women in this study were all engaged with the healthcare system, to some extent, in regard to their cancer treatment. All women received some cancer treatment. This is likely a function of the chosen recruitment methods and, in future research, a greater emphasis should be placed on recruiting women who are not receiving care within the traditional cancer care setting.

This study looked at changes in breast cancer decision making across the lifespan. Any changes noted, may be due to the cohort of the women, rather than their ages. It is possible that younger, middle-aged and older women in this study population have shared characteristics because they were born at similar times, rather than their ages. In this way, the findings are limited in that they describe these particular cohort groups.

The findings are also limited to a breast cancer population. It is unknown if this experience is similar or different from decision making experiences for patients diagnosed with other cancers or illnesses. It is possible for limitations to be mitigated in future studies by recruiting women with various diagnoses from multiple sites and utilizing a larger sample size.

Finally, the strategies involved in treatment decision making may have functions beyond making a specific decision (Baumgartner, 2011; Case, Andrews, Johnson, & Allard, 2005). Learning and information-seeking behaviours may be related to meaning-making (Collie & Long, 2005) and/or coping in cancer, yet meaning-making and coping through learning was not addressed by participants in this study. Investigating learning as coping may be an important aspect of further work in this area. If learning was found to be an effective coping strategy, there would be reason to consider facilitating informal learning processes for women with breast cancer as a part of appropriate care and support early in the cancer experience.

Summary

This thesis set out to explore the experience of decision making in the context of breast cancer from the diagnosed woman's point of view, and to develop a theoretical understanding of this process. The study also set out to meet specific objectives investigating psychosocial factors that influence decision making, the meanings that women assign to decisions, and the similarities and differences in the decision making experience between women of different ages in breast cancer. This grounded theory study was built on a review of pertinent literature; however, the findings led the authors to a specific area of study that focused on learning and information provision in breast cancer treatment decision making. Further literature reviews took place in order to situate these findings in the current literature regarding learning and information support.

As a result, the experience of decision making in breast cancer was described, and a model detailing the process was developed. The theoretical understanding, via the model, was built upon the descriptions of women about the psychosocial factors involved in decision making, as well as the meaning they made of their experiences. Barriers to information support were described and were integrated into the experience of learning in breast cancer, since information support and processes of learning are related experiences. It was found that there are many similarities between women of various ages as they experience treatment decision making, yet differences existed, particularly in the ways women of different ages learned about cancer and its treatment. The findings of this study can lead to further research regarding ways of learning for patients with cancer, and point to changes in clinical practice and policy that are guided by the perspectives of newly diagnosed patients.

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Appendix A: Recruiter Letter

Dear Study Recruiter,

I am a PhD Candidate in the Interdisciplinary Cancer Control PhD Program at the University of Manitoba. I am conducting a dissertation study that will help us to understand better how women of various ages make decisions in the context of breast cancer. This information will help us to develop better supports for women undergoing this experience.

This study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba as well as the impact committees at CancerCare Manitoba and the Breast Health Centre (Winnipeg Regional Health Authority). This study will be used to fulfill the requirements of a PhD, supervised by Dr. Roberta Woodgate.

I am writing to request your assistance in identifying potential participants for this study. Participants must be women who have been diagnosed with breast cancer of any type or stage within the past 12 months. I am seeking the participation of approximately 30 adult women with breast cancer over the next 10 months. I would like the sample to represent women across the lifespan, therefore identifying the youngest women with breast cancer would be most helpful at the beginning stages of this study.

Once identified, patients can be provided an invitation letter and a study card (enclosed). A recruitment script has also been enclosed. These women will be offered to participate in a 60-90 minute individual interview with the option to participate in a follow-up interview six to twelve weeks later. The interview questions will focus on how aspects, such as a woman's age, may influence her decision-making in breast cancer. The interview will be non-intrusive, conversational and supportive. Information on resources will be provided to all participants. All interviews will be arranged at the participant's convenience, clinic space is not required. Participants are free to withdraw from this study at any time and for any reason. All interviews will be kept strictly confidential. Codes will be used on all transcripts for any identified individuals. Direct quotations from the interviews may be used for reports and presentations but careful measures will be taken to ensure that no one can be identified.

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above persons or the Human Ethics Coordinator (HEC) at 204-474-7122.

I would greatly appreciate your help with identifying potential participants.

Thank you,

Heather Campbell-Enns, PhD Candidate
Interdisciplinary Cancer Control PhD Program, University of Manitoba

Dr. Roberta Woodgate, RN, PhD
Faculty of Nursing, University of Manitoba

Appendix B: Recruiter Script

Study Title: Decision-making across the adult lifespan in the context of breast cancer

Researcher: Heather Campbell-Enns, PhD Candidate
Interdisciplinary Cancer Control PhD Program

This research has been approved by the Education/Nursing Research Ethics Board.
If you have any concerns or complaints about this project you may contact any of the above persons
or the Human Ethics Coordinator (HEC) at 204-474-7122.

INCLUSION CRITERIA

- patient has been diagnosed with breast cancer in the past 12 months
- patient identifies as female
- at least 18 years old

There is a study being conducted about decision-making after a breast cancer diagnosis.

The purpose of this study is to understand decision-making women in breast cancer across a range of ages.

The researcher's name is Heather Campbell-Enns and, if you would like, she can provide you with more information so that you can decide if you would like to participate or not at that time.

If you are interested, she will arrange to meet with you at a time that is convenient to you. After you consent to participate, you would complete a questionnaire and then have a conversation about decision-making. You may be invited to participate in a follow-up interview later.

Of course, choosing to participate or not will not change your care. Participation in any study is completely voluntary.

You may be eligible for this study. If you are interested in obtaining more information about this study, I can give you the contact information for the researcher or, with your permission, I can provide your contact information to the researcher.

Appendix C: Letter of Invitation

Dear potential participant,

As you will know, the lives of women with cancer are complex. Many decisions must be made and some of these must be made quickly. We understand more than we used to about making decisions after cancer, but we still do not fully understand what influences a woman's decisions during the cancer experience.

This is why I am writing to you. I am a PhD Candidate at the University of Manitoba. I am conducting a study that will help us to understand how women of different ages make decisions after their breast cancer diagnosis. This information will help us to develop better supports for women undergoing this experience. I invite you to take part in this study if you have been diagnosed with breast cancer in the past 12 months. If you have already been invited to this study, please disregard this letter.

Please call or email me for more information if this interests you. I can answer any questions that you have. If you decide to participate, we can choose a time and place for an interview where I will ask you questions about making decisions after your diagnosis. The interview will take about 60-90 minutes. The interview will be a conversation where you explain to me what is important to you in decision-making. I will invite you to participate in a follow-up interview 6-12 weeks later. As a participant, you would be free to stop your participation in this study at any time and for any reason. Information on resources for persons with breast cancer will be provided to you. All interviews will be kept strictly confidential. Interviews will be transcribed and codes will be used to protect your identity and the identity of anyone else you refer to in your interview.

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above persons or the Human Ethics Coordinator (HEC) at 204-474-7122. This study will be used to fulfill the requirements of a PhD, supervised by Dr. Roberta Woodgate.

If you are interested in participating, or if you would like more information, please contact me. Thank you for considering this invitation.

Sincerely,

Heather Campbell-Enns, PhD candidate
Interdisciplinary Cancer Control PhD Program, University of Manitoba

Dr. Roberta Woodgate, RN, PhD
Faculty of Nursing, University of Manitoba

Appendix D: Poster

October 24, 2013

CancerCare
MANITOBA
ActionCancerManitoba

Decision-making:
Women with Breast Cancer

Have you been diagnosed with breast cancer in the past 12 months?

You are invited to take part in a study that explores how women with breast cancer make decisions.

Please call or email for more information.

Contact:

Name: **Heather Campbell-Enns, PhD Candidate**
Phone:
Email:

UNIVERSITY OF MANITOBA

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above persons or the Human Ethics Coordinator (HEC) at

Decision-making:
Women with Breast Cancer
Heather Campbell-Enns

Decision-making:
Women with Breast Cancer
Heather Campbell-Enns

Decision-making:
Women with Breast Cancer
Heather Campbell-Enns

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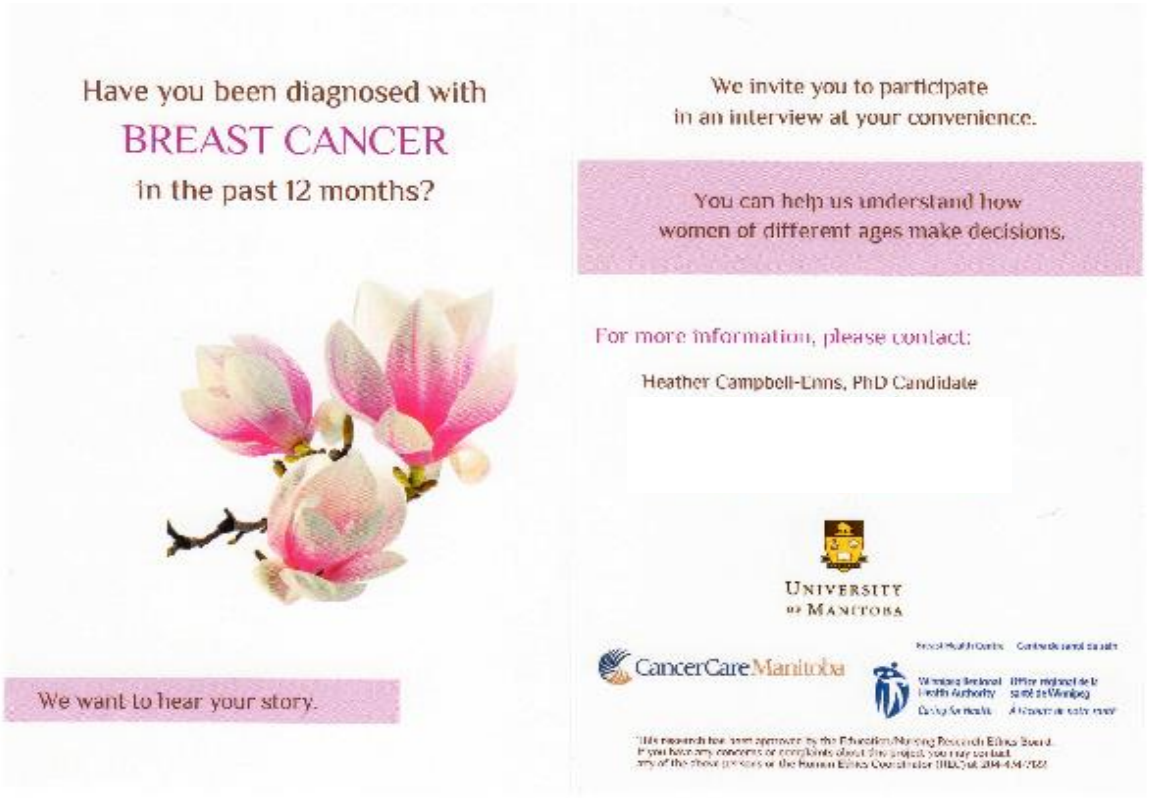
Heather Campbell-Enns

Decision-making:
Women with Breast Cancer
Heather Campbell-Enns

Appendix E: Study Postcard



Have you been diagnosed with

BREAST CANCER

in the past 12 months?

We want to hear your story.

We invite you to participate
in an interview at your convenience.

You can help us understand how
women of different ages make decisions.

For more information, please contact:

Heather Campbell-Enns, PhD Candidate

University of Manitoba

CancerCare Manitoba

Winnipeg Regional Health Authority
Office régional de la santé de Winnipeg
Caring for Health
À l'écoute de notre santé

This research has been approved by the Education/Nursing Research Ethics Board.
If you have any concerns or complaints about this project, you may contact
any of the above persons or the Human Ethics Coordinator (HEC) at 204-474-7122.

Appendix F: Letter of Consent

Letter of Informed Consent

Research Project Title:	Decision-making across the adult lifespan in the context of breast cancer
Principal Investigator:	Heather Campbell-Enns, PhD Candidate Interdisciplinary Cancer Control PhD Program
Doctoral Supervisor:	Dr. Roberta Woodgate Faculty of Nursing

Sponsor: Canadian Institutes of Health Research (Doctoral Award: CGS-D)

I am a graduate student at the University of Manitoba. I am conducting a study to explore the decision-making process of women who have been diagnosed with breast cancer.

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 detail 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.

1. Purpose of the Research

I understand that this study aims to increase understanding of decision-making among women with cancer.

2. Research Procedure

I understand that my participation in this study is completely voluntary. I understand that I will be asked to complete a background questionnaire and an interview that will focus on my approach to decision-making since my diagnosis. I am free to not respond to particular questions if I choose. The interview is expected to be approximately 60 to 90 minutes in length. I understand that I will be invited to participate in a follow-up interview in approximately six to 12 weeks by Heather Campbell-Enns and I am free to choose to not participate in the follow-up interview at that time.

3. Recording Devices

I understand that the interview will be audio recorded with a digital recorder.

4. Benefits

I understand that there are potential positive aspects to participating in this study. This is an opportunity to have someone listen to my account of decision-making in a supportive conversation and my participation may help to support women diagnosed with breast cancer in the future.

5. Risk Assessment

I understand that talking about my illness might cause some emotional distress. My feelings will be respected and I will not be asked intrusive questions. I am free to end the interview at any time. I will be given information on free counseling from CancerCare Manitoba as well as other resources and supports.

6. Confidentiality

I understand that the information I provide will be anonymous. I will be assigned a code which will be used in all written notes and transcriptions of the interview as well as in any presentations and publications that result from the study. Any other individuals to whom I refer will also be given codes. While some of my statements may be quoted in reports of the findings of this study, my identity will not be revealed. The recordings will be transcribed by Heather Campbell-Enns or a secure Canadian transcription service. A transcriptionist will sign an oath of confidentiality to ensure your privacy. All audio recordings, questionnaires and notes will be kept in a locked and secure location to which only Heather Campbell-Enns has access and all recordings will be erased after transcriptions are made. Paper forms will be shredded and electronic information will be erased upon completion of this project. After codes have replaced identifying information, copies of transcriptions will be kept in password protected computers in the office of Heather Campbell-Enns and her supervisor, Dr. Roberta Woodgate. Dr. Woodgate will erase all transcripts upon completion of the study while Heather Campbell-Enns may keep anonymous data indefinitely.

7. Compensation

I understand that the only financial compensation I will receive for taking part in this study is to cover the costs of parking during the interview.

8. Withdrawal from this study

I understand that I am free to withdraw from this study at any time by informing Heather Campbell-Enns in-person, by telephone, or by email that I do not wish to continue and data would be withdrawn from the study. This would also be confidential and there will be no negative consequences to me or my health services for withdrawing from this study.

9. Debriefing

I understand that Heather Campbell-Enns will contact me within two weeks of my final interview to debrief the interview process.

10. Dissemination of results

I understand study results will be disseminated through publications and presentations to audiences of researchers and clinicians for the purpose of furthering the understanding of decision-making across the lifespan for women with breast cancer. My confidentiality will be maintained in the dissemination of results.

11. Summary of results

I understand that I will receive a summary of the findings of this study if I wish. Heather Campbell-Enns will mail or email a brief summary of the study to me. This will occur in approximately December, 2014.

12. Destroying confidential data

All data with identifying information will be destroyed at the end of the study. The audio recording will be erased as soon as interviews have been transcribed and codes have replaced names of people and organizations. Paper forms will be shredded and electronic data linking my code and my identity will be erased at the end of the study (approximately December, 2014).

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way.

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator (HEC) at XXX-XXXX. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature: ______________________ Date: ____________________

Please provide your mailing OR email address below to receive a copy of the summary report:

Name: ____________________________Email: _______________________

Mailing address: _______________________

Town/City: __________________________

Postal Code: __________________________

Appendix G: Demographic Questionnaire

<u>Decision-making for Across the Adults Lifespan in the Context of Breast Cancer</u>

1. What is your age? ____________

2. How do you describe the place where you live? *(check one)*

___ Urban – Winnipeg or Brandon
___ Urban – Other community
___ Town
___ Rural

<u>If</u> you live outside Winnipeg or Brandon,

how long is the driving distance to <u>chemotherapy</u> treatments?

___ less than 1 hours
___ 1 – 2 hours
___ More than 2 hours

how long is the driving distance to <u>radiation therapy</u> treatment?

___ less than 1 hours
___ 1 – 2 hours
___ More than 2 hours

3. What is your marital status? *(check all that apply)*

___ Married
___ Divorced
___ Separated
___ Widowed
___ Never married
___ Member of a common-law couple

4. What is your approximate annual household income? *(check one)*

___ Under $25,000
___ $25,000 - $39,999
___ $40,000 - $49,999
___ $50,000 - $74,999
___ $75,000 - $99,999
___ $100,000 - $124,999
___ $125,000 - $149,999
___ Over $150,000

5. What, if any, is your religious preference? ___________________________

How active do you consider yourself in the practice of your religious preference? *(check one)*

___ Very active
___ Somewhat active
___ Not very active
___ Not active
___ Does not apply / Prefer not to say

6. What racial, ethnic or cultural group(s) do you identify with?

____

____

7. What is your primary language? ________________________________

8. How would you describe your current employment status? *(check all that apply)*

___ Unpaid work at home
___ Employed full time
___ Employed part time
___ On leave from paid employment
___ Looking for work
___ Student
___ Retired

9. What is your highest level of education? *(check one)*

___ Some Elementary school
___ Completed Elementary school
___ Some high school
___ Completed high school
___ Some college or university
___ Completed college or undergraduate degree
___ Some graduate school
___ Completed graduate degree

10. Who lives in your household? *Names will be kept confidential, you may also use other ways to describe these persons without names.*

Example: Daughter, age 17

____

____

11. Describe the type and stage of your breast cancer as best as you can.

____

____

12. When were you diagnosed with breast cancer? ________________________

13. Is there any other information that you would like me to know at this time?

____

____

Appendix H: Initial Interview Guide

1. What was life like before you were diagnosed with cancer?
2. What was it like to be diagnosed with cancer?
3. What has happened since you were diagnosed?
4. What is a decision making experience that you would like to tell me about?
5. Can you tell me about any treatment decisions?
6. Was there a decision that you felt you were unable to make, perhaps you felt stuck or unable to act?
7. Earlier you mentioned (decision), can you tell me more about that?
8. Is there an issue that you are currently making a decision about?
9. What do you think people should know about women your age and making decisions after a breast cancer diagnosis?
10. Is there anything else I should know to help me better understand decision making in breast cancer?

Appendix I: Follow-up Interview Guide

1. Can you tell me about any changes in your life since we met last?
2. Is there anything from our conversation that you have thought more about and you would like to tell me now?
3. Follow-up questions from initial interview.