Breast Cancer in Young Women: Examining Meanings Post Contralateral Prophylactic Mastectomy

by

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ABSTRACT

Breast cancer is the malignant growth of cells originating in breast tissue. Breast cancer primarily occurs in women aged 50-69; however, 18% of cases occur in women under 50 years of age. The diagnosis and treatment of breast cancer exerts significant stress on young women's sexuality, including reproduction, femininity, and relationships. Surgical removal of breast tissue is commonly used to treat breast cancer. Increasingly, young women with unilateral breast cancer are choosing to have both breasts surgically removed. This is known as contralateral prophylactic mastectomy (CPM). Research studies on sexuality in young women with breast cancer who have undergone CPM are limited, suggesting a gap in knowledge related to the psychosocial needs of these women. This qualitative research study used van Manen's Phenomenology to examine the research questions: 1) What meanings do young women with breast cancer ascribe to their experiences post CPM 2) What meanings do young women with breast cancer ascribe to their sexuality post CPM? A total of seven women diagnosed with unilateral breast cancer, aged 31 to 52 were interviewed and asked to describe their experiences of sexuality post CPM. The essence of these young women's experiences of sexuality post CPM is described as "My body is scarred, but for that I am stronger". The essence is supported by the three following themes: 1) My breast decision: Empower me to make informed treatment decisions about my breast health; 2) Defining a new normal for intimacy post CPM; and 3) Supporting me in coping with my chest without breasts. The uncovered meanings in this study will provide healthcare professionals with knowledge

and understanding of the psychosocial needs of these women, and elicit information to inform and advance practice to improve quality of life of young women diagnosed with breast cancer.

Keywords: contralateral prophylactic mastectomy, breast cancer, young women, sexuality

DEDICATION

I dedicate this work to my beautiful, vibrant and intelligent daughter Emma. Even though you are only eight years old, you amaze me with your incredible insight, kindness, and aspirations for making the world a better place. Never forget your amazing worth in this world; never let your dreams escape you. You have the power and strength to make all your dreams come true.

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List of Symbols, Nomenclature or Abbreviations

CBC: Contralateral breast cancer

CPM: Contralateral prophylactic mastectomy

UN: Unilateral mastectomy

BCS: Breast conserving surgery

Breast Cancer in Young Women: Examining Meanings Post Contralateral Prophylactic Mastectomy

Chapter One: Introduction

The purpose of this chapter is to introduce the topic of sexuality in young women with breast cancer following contralateral prophylactic mastectomy (CPM). A discussion of the unique psychosocial challenges that face young adults who are living with cancer is presented to facilitate an understanding of the concerns and unmet needs specific to young adults. The research method adopted for examining the research question is introduced. In addition, I have described the relevance of this research study to clinical practice in oncology.

Significance of the Problem

Cancer is a devastating disease that negatively affects the social, psychological, emotional and sexual domains of a person's life. Breast cancer is a malignant tumor that originates from the cells of breast tissue (Canadian Cancer Society [CCS], 2016; Vaidya, Joseph, & Jones, 2012). Diagnosis of breast cancer is made by a combination of three assessments: clinical examination, radiological assessment by mammography or ultrasound, and histopathological assessment by cytology or biopsy (D'Souza, Darmanin & Fedorowiez, 2011). Breast cancer is the most commonly diagnosed cancer among women with approximately 18% of cases diagnosed in women younger than 50 years of age (American Cancer Society [ACS], 2015; CCS, 2015; DeSantis et al., 2014). Young women with breast cancer possess significant psychosocial challenges that may

negatively their impact quality of life. The Canadian Cancer Society (2015) defines young women with breast cancer as those aged 20 to 44 years of age. As such, this qualitative research study focuses on the experiences of sexuality in women, aged 20 to 44 following CPM for treatment of unilateral breast cancer.

For some young women with breast cancer, treatment can have significant detrimental effects on sexuality (Fatma, Yangin & Tekeli, 2010; Katz, 2011; Kedde, van de Wiel, Weijmar Schultz & Wijsen, 2013a & b; Shell, 2008). Desire to engage in sexual behaviors and relationships are largely influenced by factors such as comfort with physical environments, perceptions of body image, and emotional and romantic attractions to partners (Lehmiller, 2014). Human sexuality is multidimensional; it extends further than penile-vaginal penetration and procreation (Fatma et al., 2010). Sexuality is unique to the individual, and it is defined by various elements such as age, genetics, gender, gender roles, and gender identity, attitudes towards sex, marriage, monogamy and polygamy, sexual behaviors and orientation, religious beliefs and cultural practices, and physical and social environments (Fatma et al., 2010; Lehmiller, 2014; Mehta, Walls, Blood & Shrier, 2014).

Cultural and societal influences on sexuality vary greatly among different parts of the world. For example, in Western cultures, sex before marriage is largely acceptable, as many young adults experience a pattern of serial monogamy, especially during their third and fourth decades of life until entering marriage or common law relationships. In contrast, premarital sex is considered unacceptable in other religions and cultures (Fatma

et al., 2010). Furthermore, societal norms and practices promoting the use of sexual imagery for sexual stimulation, such as pornography, television dramas and sit coms, and the use of the internet and social media for sexual self-expression have become normalized in Western culture, setting expectations for sexuality and sexual behavior for young adults McHugh et al., 2008; Lehmiller, 2014).

Psychological factors that influence sexuality and sexual behavior are mood states (i.e., depression, cognitive distraction), attitudes toward sex and relationship with partners, sexual expectancies, and associations learned through reinforcement (such as the experience of pain, or feelings of embarrassment related to altered body image during intimacy in women who have undergone surgical treatment for breast cancer) (Katz, 2013; Lehmiller, 2014.

Breast cancer can negatively impact the quality of life for young women (aged 20 to 44 years) differently than older women (Adams et al., 2011; Kedde et al., 2013b). Considering life-stage development, younger women have been reported to experience higher levels of depression, and have more difficulty coping with breast cancer diagnoses when compared to older women due to themes representative of young women's stage of life during this time (Adams et al., 2011; Kedde et al., 2013b). These themes include: forming quality, meaningful relationships with partners during dating, common law, and marriage; concerns about intimacy and body image; concern about reproduction and family planning; concern about career goals and fear of loss of employment, friends, and personal identity (Adams et al., 2011; Davis et al., 2010; Fobair et al., 2006; Katz, 2011;

Katz, 2014; Kedde et al., 2013a; Shell, 2008). When first diagnosed with breast cancer, young women are faced with the concept of mortality; like older women, they consider treatment options that are most likely to ensure life and longevity (Anderson et al., 2017; Davies et al., 2015; Rees et al., 2017). Furthermore, some young women with breast cancer experience disfigurement, hair loss, changes in weight, fatigue and nausea as the result of breast cancer treatment, all of which may produce negative perceptions of self as sexual beings much the same as older women (Davis, Meneses, & Hilfinger Messias, 2010; Fobair, Stewart, Chang, D'Onofrio, Banks & Bloom, 2006; Katz, 2011; Kedde et al., 2013a). Concerns about sexuality are often raised following the onset of treatment side effects and bodily changes; however, for some women, they may arise during the time of diagnosis (Katz, 2013). However, the fear of death, and consideration of treatment options that hold promise for life and longevity shift to the forefront when initially diagnosed with breast cancer (Katz, 2013). Health care providers do not often introduce the topic of sexuality, and women are not adequately informed about the consequences of their treatment choices on their sexuality (Katz, 2013). Lastly, women may not express their concerns about sexuality with health care professionals due to personal discomfort and embarrassment (Kedde et al., 2013a).

Contralateral prophylactic mastectomy (CPM) is a type of mastectomy in which the entire unaffected breast is removed along with the cancerous breast to reduce probability of developing cancer in the unaffected breast, or contralateral breast cancer (CBC). Contralateral breast cancer is a tumor that develops in the opposite breast diagnosed more

than six months after the first tumor (Frost, 2005; Unukovych et al., 2012). CPM is becoming a common treatment among young women with breast cancer because they believe it will extend life and prevent metastatic disease. The use of CPM has increased approximately 150% since 1988; however, the benefits to increasing survival depend on the estimate of risk of developing breast cancer in the future (Brewster & Parker, 2011; King, Patil, Gurevich, Stempel, Sampson, & Morrow, 2011; Pesce, Liederbach, Czechura, Winchester, & Yao, 2014). Some research suggests CPM reduces women's risk for developing breast cancer in the unaffected breast if they possess a family history or genes related to developing breast cancer (Frost, 2005; McGaughey, 2006; Unukovych et al., 2012). A recent American study reported a 24.2% CPM uptake among 2965 breast cancer patients; only 13% of those women possessed known genetic mutations in specific genes that put them at risk for developing breast cancer; these mutations occur in the breast cancer susceptibility genes I and II (BRCA I or BRCA II) (King et al., 2011). What is important to note is that only five to 10% of all breast cancers possess these mutations, therefore, approximately 90% of breast cancers are due to other genetic factors not fully identified (CCS,2016; Vaidya et al., 2012).

Physical and psychological morbidity refer to a departure from a state of physical and psychological well-being as the result of disease or illness (Lostumbo, Carbine & Wallace, 2010). Previous research has shown that some women who have opted to undergo CPM as a method to reduce breast cancer risk suffer from both physical and psychological morbidity as the result of altered body image (Lostumbo et al., 2010).

However, it is imperative to consider the psychological morbidity that women face when first diagnosed with breast cancer, and how that distress may empower them to make decisions about their breast cancer treatment and prophylaxis. Young women diagnosed with breast cancer live each day knowing that a tumor is growing inside their bodies that poses a threat to their very existence (Rees et al., 2017). As a result, they may experience heightened anxiety and emotional distress related to their diagnoses (Anderson et al., 2017; Campbell-Enns & Woodgate, 2015; Davies et al., 2015; Rees et al., 2017). How young women react to their diagnoses is dependent on their past experiences with breast cancer (Campbell-Enns & Woodgate, 2015; Rees et al., 2017). Having a close friend or family member who has either survived or been deceased from breast cancer can be anticipated to influence how young women make decisions about their breast cancer treatment. Concerns related to ensuring life and longevity shift to the forefront as they consider the personal contexts of their lives. These concerns include: the desire to live into older adulthood; desire for meaningful relationships with partners; desire for meaningful social relationships; concern for their children and families; and concerns for employment and financial security (Adams et al., 2011; Cambpbell-Enns & Woodgate, 2015; Diaconu, Maxim, Timofte & Livadariu, 2014). Therefore, women's perceived breast cancer risk must be appreciated by health care professionals when helping women make informed choices about their breast cancer treatments and health.

Women who have undergone CPM experience the loss of both breasts, which many describe as representative of their womanhood and femininity (Katz, 2013; Ruben &

Tanenbaum, 2011). Femininity refers to the quality of being female; it is socially constructed and varies depending on cultural norms and expectations (Ruben & Tanenbaum, 2011). For example, in Western culture, some young women wear makeup and clothing that flatters their natural curves of their breasts and hips to express their femininity. Womanhood refers to physical traits that women have, such as breasts and their ability provide nourishment to infants and toddlers through breastfeeding (Katz, 2013). Some women who have underwent CPM experience pain, discomfort, and diminished sensation to these areas, resulting in physical morbidity (Katz, 2013; Katz, 2014; Lostumbo et al., 2010). This may contribute to poor perceptions of self, diminished feelings of femininity and attractiveness, and decreases in sexual function and satisfaction, all of which contribute to psychological morbidity and a poorer quality of life during survivorship (Frost et al., 2005; Lostumbo et al., 2010; McGaughey, 2006). Furthermore, the loss of breasts may signify a loss in womanhood to some young women, as they no longer possess the ability to nourish their children through breastfeeding (Katz, 2013).

To date, only one study has examined sexuality in young women with breast cancer following CPM (Rosenberg et al., 2013). Previous research has focused on women of all ages diagnosed with breast cancer, rather than considering unique psychosocial and psychosexual concerns and needs of young women specifically. As the number of young women opting for CPM is increasing with questionable benefit to overall survival, it is

imperative that the psychosocial effects of this treatment option on this population be examined.

Purpose and Research Question

As humans cannot be separated from their worlds, or into parts, it is essential that health care providers seek to understand persons by considering them as whole entities in continuous interrelationship with their environments. The aim of this study was to examine the lived experience of sexuality in young women with breast cancer who have undergone a CPM. Lived experiences are everyday experiences that are described in terms of how the experience felt, or what it was like having an experience, rather than how the experience was conceptualized (Melnyk & Fineout-Overholt, 2011; van Manen, 1990). To capture this lived experience, the research questions proposed in this study were: 1) What meanings do young women with breast cancer ascribe to their experiences post CPM? 2) What meanings do young women with breast cancer ascribe to their sexuality post CPM?

This research study was conducted using qualitative research methods, specifically phenomenology. This research methodology adopted a person-centered approach, which is well suited to investigate meanings of sexuality post CPM in young women with breast cancer (van Manen, 1990). The person-centered perspective that arose from this study will enhance and strengthen traditional models of sexuality post cancer treatment and aid in interpreting young women's lived experience. Discovered meanings will provide nurses and other healthcare professionals with knowledge and greater understanding of

the psychosocial needs of these women and elicit information to inform and advance nursing practice to improve quality of life of young women diagnosed with breast cancer.

Summary

It is essential that health care providers seek to understand persons by considering them as whole entities in continuous interrelationship with their environments. It is for this reason that research about understanding human experiences of health and illness must adopt multiple ways of viewing patient realties. Phenomenology is a qualitative research approach to understanding the meanings ascribed to young women's experiences of sexuality. Information from this study provides nurses and other healthcare professions with information derived from young women's individual points of view, and contributes to improved innovative approaches to care which respond to the young women's needs, enhancing quality of life.

Chapter Two: Literature Review

This chapter reviews the literature on cancer in young adults, breast cancer and its treatment, CPM, breast reconstruction, and young women's sexuality after cancer treatment. The purpose of this literature review is to establish a body of evidence beneficial to examining the meanings young women with breast cancer ascribe to their sexuality post CPM.

Cancer in Young Adults

Individuals aged 20 to 44 years are defined by the Canadian Cancer Society (2014) as young people with cancer, accounting for 2% of all patients diagnosed with cancer in Canada (De et al., 2011). Young people with cancer face unique psychosocial challenges that negatively affect their quality of life (Katz, 2014; National Cancer Institute [NCI], 2014). These challenges include social isolation due to perceived lack of support from peers and partners, changes to their physical bodies as the result of cancer and its treatment side effects, and anxiety related to learning how to navigate complex health care systems (Katz, 2014).

Young adults face a multitude of unique challenges related to cancer diagnosis and treatment (De et al., 2011; Katz, 2014). First, the diagnosis of cancer is often delayed because young adults experiencing symptoms may not seek or have access to medical care, or they may attribute their symptoms to trauma or other situations, not to cancer (De et al., 2011; Katz, 2014). Furthermore, cancer is often not suspected early in the investigation of symptoms as health care professionals lack awareness and knowledge

related to cancer in young adults (De et al., 2011; Katz, 2014). The result is that cancers in young adults are often diagnosed at an advanced stage of disease. Regarding breast cancer in young women, detection usually occurs via the women themselves either incidentally or by performing clinical breast self-examinations, as routine mammography is generally not indicated for this age group (Canadian Task Force on Preventative Health [CTFPH], 2011). Typically, routine mammography is not indicated until 50 years of age every two to three years, unless there is a known genetic predisposition or family history of breast cancer (CTFPH, 2011). Second, cancers in young adults behave and react differently to treatment due to differences in biology of the cancers (i.e., more aggressive and less responsive to treatment) and the patient's tolerance for chemotherapy (De et al., 2011). Specifically, breast cancer diagnosed in young women under the age of 35 is associated with a poorer prognosis compared to older women due to the high rates of recurrence of regional and metastatic disease occurring earlier in life (Diaconu, Maxim, Timofte & Livadariu, 2014).

Psychologist Dr. Erik Erikson proposed a theory of psychosocial development which describes humans as passing through a series of stages necessary for social and emotional development, known as Erikson's stages of psychosocial development (Erikson, 1997). Within each developmental stage, a person must resolve a specific conflict to mature in social and emotional aspects of life (Erikson, 1997). He describes young adults as representative of the psychosocial stage "Intimacy versus Isolation" (Erikson, 1997). In this developmental stage, young adults are challenged with the

conflict of achieving intimacy versus isolation, meaning that individuals must form intimate and meaningful relationships with others to be loved, and love others (Erikson, 1997). Those individuals who cannot resolve this conflict become predisposed to experience negative romantic relationships, or their ability to form meaningful and loving intimate relationships becomes impaired (Erikson, 1997). This conflict in turn, negatively impacts the way in which individuals perceive themselves leading those individuals to form less committed relationships, and more likely to experience isolation and depression as they move into the following stages of the life cycle (Erikson, 1997). It is imperative to resolve each conflict, as one stage builds on another as a person moves through the different psychosocial developmental stages (Erikson, 1997). Resolution of this psychosocial stage is especially important for young adults with cancer. First, they may experience feelings uncertainty related to their life and longevity, diminishing their willingness to form meaningful relationships with others. They may also experience changes to their physical bodies that create insecurities related to their physical appearance. Furthermore, the changes they may experience in their physical bodies may negatively impact the way they see themselves as sexual beings, making it difficult to engage sexually with others.

Another theorist, Robert Havighurst (1948) proposed a biopsychosocial theory of development that is continuous across the life span. He asserted that developmental tasks at each life stage are influenced by individuals' personal biology, psychology, and sociology (Havighurst, 1948). Developmental tasks that arise from biological

mechanisms include walking, talking, and adapting to physical changes related to aging, whereas psychological factors include emotional maturity and forming of meaningful relationships, and establishing personal values, beliefs, morals, and goals (Havighurst, 1948). Lastly, developmental tasks that arise due to a person's unique sociology are largely influenced by the cultural beliefs and practices of that person's social environment (Havighurst, 1948). Havighurst (1948) described how resolution of challenges experienced within six stages of development is necessary for personal growth and happiness (Havighurst, 1948). The two most important stages in the context of Havighurst's (1948) theory regarding young women with breast cancer include early adulthood (18 to 35 years of age) and middle age (36 to 60 years of age) (Havighurst, 1948). Important developmental tasks for early adulthood include choosing a partner, building a home and having children, and establishing a career (Havighurst, 1948). Those tasks respective to middle age include maintaining meaningful relationships with partners, maintaining an affordable way of living, and adapting to the physiological changes associated with age (Havighurst, 1948). Young women with breast cancer experience challenges within these two stages that need to be resolved to ensure optimal quality of life. For example, some young women with breast cancer experience early menopause as the result of undergoing chemotherapy treatment; this can be very difficult for young women to cope with if having children was in their life plans. This may also cause stress within spousal relationships, as well as create insecurities in those young women who are dating.

The diagnosis of cancer during young adulthood can have significant negative impacts on quality of life, disrupting physical, psychological, social, and sexual domains of young adults' lives (Bakewell & Volker, 2005; De et al., 2011; Diaconu et al., 2014; Shell, 2008). Cancer interrupts the normative flow in which young adults work to achieve their specific developmental tasks (Campbell-Enns & Woodgate, 2015; De et al., 2011; Diaconu et al., 2014). Specifically, the diagnosis and treatment of cancer in young adults may negatively affect life goals related to careers, forming and maintaining meaningful intimate relationships, and family planning (Campbell-Enns & Woodgate, 2015; De et al., 2011; Diaconu et al., 2014; Katz, 2014; Rees et al., 2017; Shell, 2008). The adverse effects of cancer treatments (chemotherapy, biological therapy, and/or surgery) result in bodily changes such as alopecia, changes in weight, scarring and disfigurement, ultimately contributing to negative perceptions of self and diminishing quality of social relationships, sexual satisfaction and spousal relationships in some women (Archibald, Lemieux, Byers, Tamlyn & Worth, 2006; De et al., 2011; Katz, 2011; Katz, 2014). Young adults are also concerned with fertility and reproduction; however, research has indicated that many young adults with cancer are not referred to fertility specialists (Katz, 2014; Rees et al., 2017). Following completion of cancer treatments, young adults with cancer report needing post treatment support and access to services to assist them with reintegration into their previous social lifestyles, yet these services are not always available for young people, contributing to further stress, anxiety and social isolation (Katz, 2014).

Breast Cancer

Over the past decade, the incidence of breast cancer has steadily increased due to early detection of hereditary predisposition, family clustering, and mass screening (Kedde et al., 2013). In Canada and other western countries, breast cancer is the most common malignancy occurring in women (CCS, 2016; Kedde et al., 2013a). In Canada, one in nine women will develop breast cancer during their lifetime, representing 25,700 expected new cases of cancer in 2016 (CCS, 2016). Breast cancer occurs predominately in women aged 50-69 years of age (51%), with 17% of breast cancers diagnosed in women less than 50 years of age (CCS, 2016).

Types of breast cancer in young women. Breast cancer is a heterogeneous disease associated with several biological properties that determine responses to clinical treatments (Reis-Filho & Tutt, 2008). Breast cancer can occur in situ or it can invade surrounding tissues (Reis-Filho & Tutt, 2008; Vaidya et al., 2012). Breast cancer occurring "in situ" is characterized by a tumor that is confined to the original site in the breast (Vaidya et al., 2012). A tumor that has spread beyond its original site into surrounding tissues, organs, and lymph nodes is considered invasive or metastatic breast cancer (Vaidya et al., 2012).

There are many different types of breast cancer; however, certain types of breast cancer occur more commonly in younger women (Anders et al., 2009; Reis-Filho & Tutt, 2008). In young women specifically, less common, more aggressive types of breast cancer occur; these include triple negative breast cancer, basal-like breast cancer, and

inflammatory breast cancer (IBC) (Anders et al., 2009; Reis-Filho & Tutt, 2008; Vaidya et al., 2012). Triple negative breast cancers (TNBC) account for 10-17% of all breast carcinomas, usually occurring among young women under the age of 40 and women of African or Asian descent (Anders et al., 2009; Reis-Filho & Tutt, 2008). Triple negative breast cancer represents tumors that are significantly more aggressive than other molecular subtypes (Reis-Filho & Tutt, 2008) and are not positive for estrogen receptors, progesterone receptors, or overexpression of epidermal growth factor receptor 2 (HER2). Due to these characteristics, it is more difficult to treat TNBC with traditional cancer treatments.

Basal-like breast carcinomas account for up to 15% of all breast cancers and typically affect young women (Anders et al., 2009; Reis-Filho & Tutt, 2008). Basal-like breast cancers derive their name from the fact that these tumors consistently express genes usually found in the normal/basal epithelial cells of the breast (Reis-Filho & Tutt, 2008). Like TNBC tumors, basal-like breast carcinomas are significantly more aggressive than other types of breast cancer (Reis-Filho & Tutt, 2008). Inflammatory breast cancer accounts for 1-4% of all cases of breast cancer, and is usually diagnosed among young women (Anders et al., 2009; Yankaskas, 2005, 2006). Inflammatory breast cancer (IBC) begins in the cells of the breast ducts and moves into the lymph vessels in the breast tissue (Vaidya et al., 2012); resulting in symptoms like mastitis, such as edema to the breast and axillary lymph nodes, redness, warmth, nipple discharge, and breast tenderness (Vaidya et al., 2012). A lump or mass is rarely seen on mammography with IBC; instead,

IBC presents as a thickening or density of breast tissue (Vaidya et al., 2012). Biopsy is usually required for diagnosis of IBC (Vaidya et al., 2012).

Ductal carcinoma and lobular carcinoma are the two main types of breast cancer that occur in women of all age groups (Anders et al., 2009; Vaidya et al., 2012). Ductal carcinoma originates from the cells that line the ducts of the breast carrying milk from glands to the nipple (Vaidya et al., 2012). The tumor forms a lump in the breast that is either localized to the site in the breast or it metastasizes to nearby tissues (Reis-Filho & Tutt, 2008; Vaidya et al., 2012). Invasive ductal carcinoma is the most common type of invasive breast cancer, accounting for up to 80% of all invasive breast cancers. It is more is commonly diagnosed as invasive in young women than older women (Vaidya et al., 2012; Yankaskas, 2005, 2006). Lobular carcinoma originates in the cells of the lobules of the breast, the groups of glands that produce milk during lactation (Vaidya et al., 2012). Lobular carcinoma in situ (LCIS) is not usually discovered during clinical breast exams or mammograms; it is usually found after a biopsy for a suspicious lump or abnormal mammogram (Vaidya et al., 2012). Invasive lobular carcinoma is found more commonly in younger women in comparison to older women (Yankaskas, 2005, 2006).

Breast cancer that has metastasized to distant tissues, organs or lymph nodes is normally incurable and treatment goals are aimed at improving life expectancy, palliating symptoms, and improving quality of life (D'Souza et al., 2011; Vaidya et al., 2012). Commonly, the lungs, bone, and liver are sites of metastatic spread of breast cancer.

Survival is directly related to the extent of tumor involvement of these organs, tumor size, and lymph node involvement (D'Souza et al., 2011; Vaidya et al., 2012).

Phenotypical characteristics, signs and symptoms of breast cancer in young women. Breast cancer can be discovered by young women through self-examination of the breast and surrounding tissue, or it can be identified by a health care professional during a clinical breast exam, mammography, or needle or surgical biopsy (Anders et al., 2009). Breast carcinomas in young women typically exhibit more aggressive characteristics than those seen in older women, such as a larger tumor size, a higher incidence of poorly differentiated tumors (tumors that lack distinct morphology and immunohistochemical characteristics of breast tissue cells), increased expression of HER2, and absence of endocrine receptors such as estrogen and progesterone (Anders et al., 2009). These characteristics are associated with a poorer prognosis for younger women with breast cancer (Anders et al., 2009; Pollan, 2010). Younger women often possess positive lymph nodes near the site of regional cancer, meaning that the cancer has spread into the lymph tissue, a situation which contributes to a poorer prognosis in young women compared with older women (Anders et al., 2009; Yankaskas, 2005, 2006). Young women with breast cancer often present with tumors that are diagnosed at a later stage of disease in comparison to older women with breast cancer. This is due to lack of recognition of symptoms by both young women and health care providers, and the fact that mammography screening is generally not conducted on women less than 50 years of age unless genetic predisposition and heritability is present (CTFPH, 2011; Yankaskas,

2005, 2006). Last, young women with breast cancer present with a higher proportion of p53 mutations (a tumor suppressor gene, whose normal function is to suppress proliferation of cancer cells) and have higher proliferation of cancer cells in comparison to older women (Yankaskas, 2005, 2006).

Breast cancer may present as a fixed, hard, irregularly shaped lump in the breast that does not disappear with menstruation (Vaidya et al., 2012). A cancerous lump may feel tender, but not painful, and may be accompanied by small lumps extending into the axilla, indicating lymph node involvement and metastases (D'Souza et al., 2011; Vaidya et al., 2012). Additional characteristics of the disease include a change in the breast shape or size, and skin changes such as *peau d'orange*, a condition in which the skin of the breast becomes: thickened, dimpled, reddened, edematous, warm, and pruritic. (D'Souza et al., 2011; Vaidya et al., 2012).

The signs and symptoms of metastatic breast cancer depend on the extent of spread to surrounding and distant tissues and organs (Reis-Filho & Tutt, 2008; Vaidya et al., 2012). They often include bone pain, anorexia due to increased metabolism of breast cancer cells limiting nutritional availability for the rest of the body, pleural effusions, shortness of breath, cough, headache, double vision, and muscle weakness (Vaidya et al., 2012).

Risks associated with the development of breast cancer in young women. There are many known risk factors associated with the development of breast cancer in young women. These risk factors include cancer history (personal and familial), genetic

mutations, breast density, estrogen exposure, and ionizing radiation exposure (Centers for Disease Control and Prevention [CDC], 2014; NCI, 2014; Pollan, 2010; Yankaskas, 2005, 2006). Having had breast cancer once increases the probability of developing breast cancer again, either in the same breast or the unaffected breast (CDC, 2014; Pollan, 2010; Yankaskas, 2005, 2006). The risk of developing contralateral breast cancer is approximately four to five times greater for women younger than 45 years who have invasive, unilateral breast cancer who possess a family history or have inherited BRCA I and II mutations (Anders et al., 2009; Yankaskas, 2005, 2006). Furthermore, the risk for developing contralateral breast cancer increases inversely with age for young women (Anders et al., 2009; Yankaskas, 2005, 2006). However, if there is no family history or no genetic predisposition such as mutations in the breast cancer genes BRCAI or BRCAII, the risk of developing contralateral breast cancer is rare (Lostumbo et al., 2010).

A family history of breast cancer increases the risk of developing breast cancer (Anders et al., 2009; CTFPH, 2011; CDC, 2014; NCI, 2014; Werner-Lin, Ratner, Hoskins & Lieber, 2015; Yankaskas, 2005, 2006). The increased risk is observed when first-degree relatives are diagnosed with breast cancer (such as mother, sister or daughter), or second-degree relatives (such as grandmother, niece, or aunt) from either the mother or father's side of the family (CTFPH, 2011; CDC, 2014; Werner-Li et al., 2015; Pollan, 2010). In addition, young women are more likely to develop breast cancer if other relatives had breast or ovarian cancer (CTFPH, 2011; CDC, 2014; Werner-Li et al., 2015; Pollan, 2010; Yankaskas, 2005, 2006). Mutations in tumour suppressor genes BRCA I

and BRCA II, which control the growth of cancer cells, are related to developing breast cancer (CDC, 2014; Werner-Li et al., 2015; Pollan, 2010; Yankaskas, 2005, 2006). Mutations in these tumour suppressor genes cause the genes to be turned off, allowing for deregulation of normal cell cycle control leading to cancerous growth in breast cells (CDC, 2014; NCI, 2014; Pollan, 2010). These mutations are passed from parent to child and occur in one in 500 people (CDC, 2014). These mutations are responsible for about 5-10% of all breast cancers in women and usually develop into breast cancer before the onset of menopause, affecting younger women more frequently (CDC, 2014; Pollan, 2010; Werner-Li et al., 2015; Yankaskas, 2005, 2006). Women of Ashkenazi Jewish ancestry are at greater risk of developing breast cancer due a higher occurrence of BRCA mutations; 1 in 40 Ashkenazi Jewish women carry the mutations compared to 1 in 500 women of the general population (CDC, 2014; Pollan, 2010; Yankaskas, 2005, 2006). In addition, women of Black ethnicity are at greater risk for developing breast cancer than women who are white (Davis, Cantor, & Brewtser, 2015; Yankaskas, 2005, 2006).

Young women with dense breasts are at greater risk of developing breast cancer than women with less dense breasts (Anders et al., 2009; CDC, 2014). Dense breast tissue, an inherited trait, contains larger amounts of connective, gland and milk duct tissues than fatty tissue and are more common in younger women as connective and milk duct tissues decrease with increasing age (Anders et al., 2009; Vaidya et al., 2012). Women with 75% or denser breast tissue are four to six times more likely to develop breast cancer than women with little or no dense breast tissue (Anders et al., 2009). In

addition, exposure to ionizing radiation to the chest, neck and armpit area increases the risk of developing breast cancer as it damages healthy cellular DNA in these areas (Vaidya et al., 2012).

Estrogen is the main hormone associated with the development of breast cancer, as it affects the growth of cells. The length of exposure to estrogen affects breast cancer risk (CDC, 2014; Pollan, 2010; Vaidya et al., 2012). Early menarche (age 11 or younger) increases the risk of developing cancer because of a longer exposure of cells to estrogen. Pregnancy interrupts the exposure to breast cells to circulating estrogen, lowering the total number of menstrual cycles a woman has in her lifetime (Pollan, 2010; Yankaskas, 2005, 2006; Vaidya et al., 2012). Women who have had their first full term pregnancy after the age of 30 are at greater risk for developing breast cancer than those who have had a child at an earlier age; the more children a woman has the greater protection she may have against breast cancer (CDC, 2014; Pollan, 2010; Yankaskas, 2005, 2006). In addition, taking hormone replacement therapy containing both estrogen and progesterone for five years or more increases the likelihood of developing breast cancer; however, this is more likely to occur in older women (Vaidya et al., 2012). Oral contraceptives containing both estrogen and progesterone can slightly increase the risk of developing breast cancer among women who have used oral contraceptives for more than 10 years (CDC, 2014; Pollan, 2010; Yankaskas, 2005, 2006). Furthermore, alcohol, smoking, and a sedentary lifestyle have been linked to the development of breast cancer in young women (Vaidya et al., 2012).

Breast cancer treatment for young women. Breast cancer is commonly treated by surgery, chemotherapy, radiation therapy, and biological/endocrine therapy. These cancer treatments are used individually, or in combination as neo-adjuvant or adjuvant treatments (Katz, 2011; Vaidya et al., 2012). Primary breast cancer treatment refers to the main type of treatment that will provide the best therapeutic outcome for women. Often, this is surgical removal of the breast cancer tissue. Neo-adjuvant treatments are those that occur before the primary treatment, such as surgery or radiation to remove or reduce the size of a tumor preceding chemotherapy. Adjuvant treatments are treatments that occur following the primary treatment, such as surgery following radiation to reduce the size of the tumor so that it becomes operable. Breast cancer treatment regimens depend on the type of the breast cancer at the time of diagnosis, with consideration given to tumor size, metastasis to surrounding tissues, hormone involvement, age, lifestyle, reproductive history and accompanying comorbidities (Odle & Els, 2014; Vaidya et al., 2012).

Women may have surgical biopsies of the breast or lymph nodes during the diagnosis process (Odle & Els, 2014; Vaidya et al., 2012). Women with early-stage breast cancer may undergo a lumpectomy or mastectomy (Katz, 2011; Odle & Els, 2014; Vaidya et al., 2012). A lumpectomy, otherwise known as breast conserving therapy, is the removal of part of the breast such as a lump or small tumor along with excision of a small amount of tumor margin or normal surrounding tissue (Katz, 2011; Odle & Els, 2014; Vaidya et al., 2012). Following a lumpectomy, women commonly receive radiation therapy to irradiate the area in which the cancer was excised to decrease the risk of

metastases (Odle & Els, 2014; Vaidya et al., 2012). If the cancer is widespread upon diagnosis, or there are suspicious areas of calcification, a mastectomy is performed in efforts to reduce the probability of metastatic disease (Odle & Els, 2014; Vaidya et al., 2012). A mastectomy is the removal of the entire breast tissue along with the axillary tail, the nipple, muscle, and some of the breast skin, leaving a scar across the woman's chest (Harmer, 2012; Loukas et al., 2011; Rosenberg et al., 2013; Vaidya et al., 2012).

Women who have undergone surgical treatment for breast cancer often experience adverse acute and chronic physical and psychological effects (Lostumbo et al., 2010; Odle & Els, 2014). Some physical complaints consist of pain and numbness to the chest wall, breast, and axilla, lymphedema to the affected side, aching muscles, decreased range of motion, unanticipated reoperations, infection and scarring (Godflam et al., 2004; Frost et al., 2005; Katz, 2011; Odle & Els, 2014). Adverse psychological effects may include poor body image and perception of femininity, diminished self-esteem and sexual self-image, decreased quality of sexual relationships, decreased sexual responses and poor quality of life (Anderson et al., 2017; Davies et al., 2015; Frost et al., 2005; Katz, 2011; Lostumbo et al., 2010; Odle & Els, 2014).

Radiation therapy is commonly used in the treatment of breast cancer following a lumpectomy or mastectomy to destroy remaining cancer cells in attempts to decrease probability of recurrence or metastatic spread (Katz, 2011; Odle & Els, 2014; Vaidya et al., 2012). Whole breast radiation involves a series of radiation treatments to the surgical cavity delivered daily over a five-day period for five to seven weeks to prevent local

recurrence (Odle & Els, 2014). Partial breast radiation typically consists of five days of radiation to the surgical cavity and small margin of normal surrounding tissue (Odle & Els, 2014). Adverse effects of radiation treatment include moderate to severe skin reactions such as burns, erythema, fibrosis, ulceration, inflammation, skin cell necrosis and scarring which may result in pain and discomfort during caressing in intimate situations (Odle & Els, 2014; Katz, 2011; Vaidya et al., 2012). Radiation combined with surgery to the breast may result in lymphedema, late cardiac toxicity, and pneumonitis (Odle & Els, 2014). In addition, radiation causes fatigue, which affects sexual interest and activity in the short-term, and can also result in immunosuppression, increasing the likelihood of secondary infections and subsequent cancers (Katz, 2011). Depending on where women are located geographically, radiation therapy can become a financial burden as regimens include daily treatments for several weeks. Women must travel every day to receive their radiation treatment which limits their time, and results in increased financial cost considering mileage, parking, and lodging if required.

Chemotherapy can be administered to women as neo-adjuvant or adjuvant treatment, depending on the type of tumor, its size and differentiation, lymph node status and hormone involvement to manage metastatic spread of the disease (Odle & Els, 2014; Vaidya et al., 2012). Depending on the chemotherapy regimen, adverse effects of treatment include gastrointestinal complications such as nausea, vomiting, and diarrhea, as well as other side effects including alopecia, immunosuppression and myelosuppression, fatigue, decreased appetite leading to weight loss, and peripheral

neuropathy (Odle & Els, 2014). Premature menopause occurs in young women as result of ovarian suppression, often leading to temporary or permanent cessation of menses (Katz, 2011; Odle & Els, 2014). Suppression of function of the ovaries leads to hot flashes, vaginal dryness, vulvovaginal atrophy, dyspareunia (constant or recurrent genital pain in association with sexual intercourse), loss of libido and infertility, all resulting in altered sexuality (Katz, 2011; Kedde et al., 2013a; Odle & Els, 2014).

Endocrine or biological therapy is administered following chemotherapy as an adjuvant treatment to specifically target the receptors of cells responsible for cancer cell growth and proliferation in breast cancer, depending on hormonal involvement in breast cancer development (Odle & Els, 2014; Vaidya et al., 2012). Endocrine therapies such as anti-estrogen drugs reduce the risk of breast cancer recurrence, and can be used singularly or in combination for a maximum of five years following chemotherapy (Archibald et al., 2006; Odle & Els, 2014). Adverse effects of antiestrogens include musculoskeletal and joint pain, osteoporosis and bone fractures, changes to vaginal thickness, risk of endometrial cancer, and central nervous system contributing to changes in women's bodies and sexuality (Archibald et al., 2006; Odle & Els, 2014).

Risk reducing surgery. Contralateral breast cancer (CBC) is the most common second primary cancer in breast cancer patients (Davies et al., 2015). It is estimated to account for 30% to 50% of all second breast cancers (Davies et al., 2015). Contralateral prophylactic mastectomy (CPM) is commonly performed for the prevention of breast cancer in an unaffected, healthy breast in women with unilateral breast cancer

(Davies et al., 2015; Lostumbo et al., 2010). There is limited oncologic benefit in preventing future breast cancers or recurrences by performing CPM in women who do not possess BRCA I and II mutations, or possess a familial history of breast cancer (Davies et al., 2015; Lostumbo et al., 2010). Routine surveillance is recommended for monitoring the contralateral breast, and contributes to early detection and curative treatment of contralateral breast cancer (Richards et al., 2016). Routine surveillance includes clinical examination, mammography testing in women 50 years of age and older, magnetic resonance imaging (MRI) if required, possible diagnostic surgeries and chemoprevention (Baker, Mayer & Esposito, 2013; CTFPH, 2011; Zendejas, Moriarty, O'Bryne, Degnim, Farley & Boughey, 2011). In the United States, both CPM and routine surveillance are comparable in cost, with the mean costs of CPM and routine surveillance estimated to be $36, 594 and $35, 182 (Zendejas et al., 2011).

The use of CPM has greatly increased over the last decades; it has been reported to be associated with four main factors: younger age, White race, year of diagnosis and desire for breast reconstruction (Agarwal et al., 2015). While CPM reduces relative contralateral breast cancer (CBC) risk by 90-95% in certain groups of patients (younger women with BRCA I or II mutations and those with a strong familial history of breast cancer) (Davies et al., 2015; Richards et al., 2016; Zendejas et al., 2011). Research examining the benefit of CPM in prolonging survival is controversial, with no clinical benefit extending to most women (Davies et al., 2015; Richards et al., 2016; Zendejas et

al., 2011). Women may choose to undergo CPM to reduce the risk of developing cancer in the unaffected breast (Lostumbo et al., 2010; Odle & Els, 2014).

Traditionally, CPM has been reserved for women who are at high risk for developing breast cancer in the contralateral breast (e.g., those with family history of breast cancer and genetic mutations such as BRCA I and II) (Brewster & Parker, 2011; Lostumbo et al., 2010). In the literature, there is debate about the actual risk of developing CBC. Some studies report the annual risk of future developing CBC to be approximately 0.5%, with a range of 0.19% to 0.75% (Anderson et al., 2017; Davies et al., 2015; McLaughlin, Lillquist & Edge, 2009; Tuttle, Habermann, Abraham, Emory & Virnig B, 2007). Another study conducted by Reiner et al. (2013) defined this risk as being greater, at approximately 5% for these women (Jerome-D'Emilia, Suplee & D'Emilia, 2015). In contrast, CBC risk has been identified to be higher in women with a BRCA I or II mutations, with rates estimated to fall between three to four percent, and as high as 18% in some studies (Agarwal et al., 2015; Jerome-D'Emilia et al., 2015; Reiner et al., 2013; Tesson et al., 2017). However, one study reported The Society of Surgical Oncology (2007) recommend CPM to be performed on 1) women who have BCA I and II mutations, or on who have a family history of breast or ovarian cancer in multiple first degree relatives, 2) on those difficult to surveillance due to breast density or calcifications, and 3) on those women who are considering bilateral breast reconstruction.

Despite the low risk of developing CBC, many women are seeking CPM even when they are not truly at risk for developing breast cancer in the contralateral breast

(King et al., 2011). Furthermore, recent studies have shown that surgical oncologists have discomfort with performing the procedure on women who do not have a deleterious BCRA mutation for reasons which include a concern for over treatment, an unfavorable risk/benefit ratio, and inadequate patient understanding of the anticipated risks and benefits of CPM (Bellavelance et al., 2016). The inadequacy of patient understanding is an area for concern, as it identifies the need for better communication and counselling from health care providers to women with breast cancer regarding their personal risks of developing CBC, and the risk/benefits of CPM from a holistic view point. Health care providers have a legal obligation to ensure that young women with breast cancer fully understand their diagnoses, and options for treatment with anticipated risks and benefits to undergoing each option. If they are unable to provide such education and counseling, then these women must be referred on to another professional who can provide these services to ensure adequate understanding, and facilitate informed decision making with the women's concerns at the forefront.

Young women are choosing to have CPM because they believe it will reduce the risk of CBC, prevent metastatic disease, improve survival and alleviate anxiety and stress (Anderson et al., 2017; Davies et al., 2015; Lostumbo et al., 2010; Rosenberg et al., 2013). It has been suggested that young women overestimate their cancer risk and that genetic counseling about breast cancer risk is needed to help women, especially with a low breast cancer risk, achieve more accurate risk perceptions (Lostumbo et al., 2010; King et al., 2011).

A recent cross sectional study conducted by Rosenberg et al. (2013) examined factors that led young women with breast cancer to choose to undergo CPM. Approximately one quarter of the young women who underwent CPM were carriers of BCRA I and BRCA II mutations (Rosenberg et al., 2013). Of the total sample, only 26% of women had a family history of breast cancer affecting a first degree relative, followed by 62% of women who had a second or third degree relative with the disease (Rosenberg et al., 2013). The main reasons women sought to undergo CPM included a desire to decrease probability of developing CBC, the desire for peace of mind and longevity, as a strategy to decrease probability of metastases, feeling at risk for developing CBC, alleviation of anxiety related to developing CBC, and having a family history of breast cancer, followed by physician recommendations and the desire for both breasts to look the same following surgery (Rosenberg et al., 2013). The physicians were cited as the main source of information regarding decisional analysis related to undergoing CPM, however, only 51% of the women reported that their physicians had given reasons not to undergo CPM (Rosenberg et al., 2013). Furthermore, the results of the study reported that 42% of the women felt that their sense of sexuality was worse than expected; one third of the women identified feelings of self-consciousness regarding attractiveness following CPM (Rosenberg et al., 2013).

A recent population based study conducted by Katz et al. (2017) further examined the association between clinical counselling and women's decision making regarding CPM. The study examined whether surgeons discussed the specific benefits and risks of

CPM considering (1) survival, (2) recurrence of treated cancer, (3) occurrence of new contralateral cancer, (4) cosmetic outcomes, and (5) recovery from surgery by asking them to describe their experiences of counselling. Approximately 26% of participants reported that their surgeon recommended against CPM for reasons not identified, while 32% of participants reported no significant discussion of CPM (Katz et al., 2017).

Another study conducted by Anderson et al. (2017), examined the long-term effects on body image and satisfaction among women with unilateral breast cancer who opted to undergo CPM versus breast conserving therapy (BCS) and unilateral mastectomy (UM). Although the study found that overall patient satisfaction among both CPM and UM groups were high (97% and 89% respectfully), body image was reported to be lower among CPM groups versus BCS groups, and even lower among women in CPM groups who did not undergo breast reconstruction (Anderson et al., 2017). High patient satisfaction with CPM has also been reported in other studies (Katz et al., 2017). Women in CPM groups reported increased self-consciousness and poor perception of body appearance compared to the other surgical subgroups (Anderson et al., 2017). Anderson et al a (2017) also found that women who had BCS scored highest pertaining to feeling whole in terms of their body, and sexually attractive when compared to CPM and UM groups (Anderson et al., 2017). Furthermore, CPM resulted in a higher rate of breast reconstruction when compared to UM (70% versus 47%) (Anderson et al., 2017). Younger women were found to choose breast reconstruction after CPM more often than those who chose UM (Anderson et al., 2017). The results of this study highlight that

although CPM may have negative impacts on body image and sexuality, women are satisfied with their choice and would choose to undergo the surgery again for a variety of psychological benefits (Anderson et al., 2017).

The results of these studies indicate the need for enhanced education and counselling regarding risk of CBC in young women with breast cancer. Furthermore, results suggest that young women with breast cancer who undergo CPM may experience altered perceptions of body image negatively affecting sexuality, yet do not experience a diminish in overall quality of life (Anderson et al., 2017; Rosenberg et al., 2013).

Following breast cancer and its treatment, women attempt to regain normalcy in their lives as they enter survivorship (Rees, 2017). They are challenged with various uncertainties related to their future. These uncertainties include fear of breast cancer recurrence and having to endure all the challenges that accompany the diagnosis such as: breast cancer treatments and side effects, financial burdens related to attending appointments and treatments, disruptions to family, social life, and career, and ultimately fear of death. Furthermore, women with a history of breast cancer face uncertainties related to their sexuality, such as changes to body image and intimacy, as well as body challenges related to family planning considering possible premature menopause and infertility (Rees, 2017). Collectively, women with unilateral breast cancer examine their uncertainties in the context of their treatment options in efforts to normalize their lives after cancer (Rees, 2017).

It has been reported that approximately 80% women who undergo CPM are satisfied with their mastectomy choice as well-being and quality of life were not reported to be negatively influenced (Anderson et al., 2017). The potential benefits of CPM include a decreased risk of developing cancer in the unaffected breast and a decrease in anxiety related to breast cancer development in the unaffected breast (Davies et al., 2015; Lostumbo et al., 2010). This positively impacts the psychological well-being of women with unilateral breast cancer as it removes the imminent threat of death from their lives. A recent study conducted by Rees (2017) examined the experiences of regaining normalcy in young women with breast cancer. The author identified that young women with breast cancer experienced significant uncertainty related to treatment effectiveness and fear of recurrence (Rees, 2017). These young women experienced heightened levels of stress when faced with the threat of a shortened life span, and mortality (Rees, 2017). They considered their probability of developing a second breast cancer as high given their young age as compared to women diagnosed at older ages (Rees, 2017). Given these uncertainties, CPM may be considered an effective and appropriate treatment option for young women with breast cancer through psychological benefit.

Other potential benefits to CPM include improved cosmetic outcome to women's breasts following breast reconstruction. Removing both breasts offers a greater probability of undergoing breast reconstruction that results in breasts that are equal in size and symmetrical, especially if radiation therapy has not been required (Anderson et al., 2017; Davies et al., 2015). This can be anticipated to result in improved perceptions of

body image, attractiveness, and femininity in some young women who experience disturbances in sexuality resulting from body image issues (Anderson et al., 2017; Davies et al., 2015). A study conducted by Tesson et al., 2017 indicated that approximately 27% of the women in their sample chose CPM for reasons other than risk reduction. These women chose CPM for their desire to have breast symmetry following breast reconstruction, suggesting that women may request CPM for reasons related to body image disturbance in addition to reducing CBC risk (Tesson et al., 2017).

The potential disadvantages of CPM, some of which have been noted earlier include the invasiveness of the procedure resulting in physical morbidity negatively affecting quality of life (Davies et al., 2015; Lostumbo et al., 2010). Also, there is a greater risk of complications from surgery compared with primary mastectomy, which may delay the commencement of adjuvant treatment (Richards et al., 2016). In addition, CPM has been reported to negatively affect self-esteem and sense of femininity, body image, perceptions of physical attractiveness and sexual relations (Anderson et al., 2017; Davies et al., 2015; Frost et al., 2005; McGaughey, 2006; Richards et al., 2016; Unukovych et al., 2010). Furthermore, CPM does not guarantee removal of all breast tissue; therefore, it cannot eliminate all risk for developing the breast cancer (Lostumbo et al., 2010). Despite these disadvantages, retrospective studies have shown that women within all risk groups have a high rate of satisfaction with CPM (Anderson et al., 2017; Davies et al., 2015; Frost et al., 2011).

Although there is little difference in cost between CPM and routine surveillance, it can be argued that costs associated to women with breast cancer is not always considered. Having a unilateral mastectomy may result in imbalances in symmetry if women choose to undergo breast reconstruction (Davies et al., 2015). For some women, this results in unanticipated operations to correct asymmetries and to improve cosmetic outcome; it may also result in surgical complications such as infection (Anderson et al., 2017; Davies et al., 2015). Other costs to women with breast cancer include financial burdens, such as travel time and expenses to attend appointments and treatments and purchasing appropriate fitting breast prostheses. A person-centered perspective evaluating the costs to women highlights the psychological and emotional costs as most important to consider when weighing clinical treatment options. These include stress and anxiety related to fear of recurrence of breast cancer, and the time and energy these women endure performing self-breast exams and seeking care from health care providers when concerns arise (Anderson et al., 2017; Rees et al., 2017). In this way, CPM can be considered cost saving to the women, and may be the best treatment option for women who perceive their risk of CBC as high. In other ways, CPM may be considered cost saving to the health care system, as women may not seek health care services such as clinical breast exams and radiological imaging for concerns about their breasts if they have undergone CPM.

Psychosocial concerns of young women with breast cancer

Young women living with cancer are faced with a multitude of challenges that negatively affect social, psychological, physical, and sexual domains of their lives

(Bakewell & Volker, 2005; De et al., 2011; Shell, 2008). In this regard, protective factors that have been identified for young women with breast cancer include strong supportive networks engrained in social, familial, and spousal relationships, and timely referrals to specialized services, such as plastic surgeons for breast reconstruction and therapeutic counselling (Campbell-Enns & Woodgate, 2015). Multiple studies have noted that women who are diagnosed with breast cancer at a young age experience more emotional distress, anxiety, and depression compared to those who are diagnosed in older years (Adams et al., 2011; Anderson et al., 2017; Campbell-Enns & Woodgate, 2015; Davies et al., 2015; Diaconu et al., 2014). This difference in the ability to cope with breast cancer diagnoses between the two groups may be due higher levels of psychosocial adaptation among older women, as the result of having more life experience (Campbell-Enns & Woodgate, 2015). The life experiences that are believed to help shape older women's adaptation to their illness include having prior experiences with the health care system, having personal experience of breast cancer through the diagnosis of a loved one, and having less competing demands such as employment and financial concerns (Campbell-Enns & Woodgate, 2015). Furthermore, older women with breast cancer may cope with breast cancer better than younger women with breast cancer due to prior resolution of psychosocial stages associated with young and middle adulthood. For example, older women diagnosed with breast cancer may possess less stress and uncertainty related to the care and well-being of their children as they are older and independent. This contrasts

with younger women with breast cancer, as they are concerned with raising their dependent children and ensuring their health, well-being, and safety.

Breast cancer and its treatment is often associated with increased financial burden to younger women in comparison to older women (Campbell-Enns & Woodgate, 2015; Diaconu et al., 2014). Due to the lengthy treatment process which consists of surgery, chemotherapy, radiation and endocrine therapy in isolation or combination, women with breast cancer may be forced to take time away from their careers, which decreases their financial income (Campbell-Enns & Woodgate, 2015; Diaconu et al., 2014). Furthermore, there is increased costs associated with attending treatment appointments and follow up for breast cancer (mileage costs, parking, hospitality); this is especially pronounced if the woman lives geographically distant from the treatment center. For some young women, they balance the demands of their financial responsibilities by continuing to work, despite feeling unwell (Adams et al., 2011).

In addition to financial stress, young women are challenged with competing demands of family roles and responsibilities (Adams et al., 2011; Campbell-Enns & Woodgate, 2015). They must balance competing demands by putting their own needs first to promote their personal well-being to better care for their family (Adams et al., 2011). Often the partners of young women with breast cancer assume more household responsibilities, particularly during treatment times (Adams et al., 2011; Campbell-Enns & Woodgate, 2015). For single mothers dealing with breast cancer, balancing competing demands of self-care versus the care of their children and household tasks becomes much

more difficult, as they lack spousal support. Furthermore, mother to child interactions have also been reported to increase during breast cancer, as well as enhanced family relationships (Campbell-Enns & Woodgate, 2015). Young women, who are not mothers, balance their own desire for children against the possibility of early menopause and infertility that arises with certain treatments (Adams et al., 2011).

Assessment of women's perceptions of risk should seek to understand the women's past personal experiences with breast cancer, and how they shape the decision-making process when balancing treatment choices. Lastly, younger women with breast cancer may experience increased loneliness compared to older women; this is thought to be due to younger women perceiving themselves as different from their peers and out of sync (Adams et al., 2011; Campbell-Enns & Woodgate, 2017). Their social relationships are believed to be less established than those of older women and more vulnerable to stress (Adams et al., 2011). As a result, younger women may feel socially isolated, lacking social support (Campbell-Enns & Woodgate, 2015).

Young women with cancer have reported psychosocial concerns about personal identity, self-esteem, body image and femininity, reproduction, quality of intimate and spousal relationships, attractiveness, caregiving, and premature menopause (Campbell-Enns & Woodgate, 2015; Davis et al., 2010; Katz, 2011; Kedde et al., 2013b; Kinamore, 2008; Taghian et al., 2010). Cancer and its treatment negatively affect individuals' sexuality, intimacy, self-esteem and quality of sexual relationships with partners (Katz, 2012; Kedde et al., 2013b). Sexuality plays a pivotal role in quality of life, and presents

as a concern for cancer patients and cancer survivors (Katz, 2012; Kedde et al., 2013b). It defines individuals in terms of who they are, encompassing pleasure, self-image, and their relationships to others (Katz, 2012). Components of sexuality include sexual activity, sexual function, and intimacy (Katz, 2012). Approximately 80% of cancer survivors have concerns about their sexuality as the result of cancer treatment (Katz, 2012).

Research indicates that many of these psychosocial concerns, specifically sexuality, are not addressed by health care providers, leading to gaps in quality oncology care and diminished quality of life for women (Katz, 2011; Kedde et al., 2013b). Health care professionals are reluctant to discuss sexuality due to a lack of knowledge and expertise, differences in cultural and religious beliefs, personal comfort with sexuality, and feeling as though it is not their responsibility to approach the topic (Katz, 2012; Kedde et al., 2013a & b). However, when health care professionals are willing to discuss sexuality, the responsibility to initiate conversation around the topic may be left to the patient, which in many instances, is difficult for patients who may feel embarrassed or whose primary concern is recurrence and living (Katz, 2012; Kedde et al., 2013b).

As noted in the introduction chapter of this thesis, breast cancer disrupts the achievement specific developmental tasks required to grow and mature into healthy middle aged women. These important tasks can include forming quality, meaningful relationships with partners during dating, common law, and marriage; intimacy and body image, concern about reproduction and family planning, career goals, fear of loss of

employment, peer relationships, and personal identity (Adams et al., 2011; Davis et al., 2010; Fobair et al., 2006; Katz, 2011; Katz, 2014; Kedde et al., 2013a; Shell, 2008). Health care providers, including nurses, are required to examine how the diagnosis of breast cancer in young women challenges achievement of developmental tasks through a holistic lens, to ensure quality of life throughout the cancer trajectory.

Furthermore, health care providers and nurses have a duty to provide young women with breast cancer with knowledge of their personal CBC risk, and risks and benefits to undergoing treatment options such as CPM. Nurses play an important role in empowering young women with breast cancer to make informed choices regarding their health.

Sexuality following breast cancer and CPM in young women. The diagnosis and treatment of breast cancer can have significant negative effects on a young woman's sexuality and quality of life (Katz, 2011). Young women experience more distress related to sexuality, body image, fertility, and more depression compared to older women (Katz, 2011). For young women specifically, a major psychosocial challenge remains normalizing life after breast cancer in the context of their bodies post treatment (Adams et al., 2011). Depending on the type of breast cancer treatment, women may experience fatigue, loss of libido, dyspareunia, alopecia, decreased arousal in response to sexual stimuli, vaginismus (involuntary muscle contraction of the vagina during penetration), vaginal atrophy, vaginal irritation, and numbness to breasts and nipples (Katz, 2011; Kedde et al., 2013a; Ussher, Perz & Gilbert, 2012). These negative side effects diminish

sexual responses to women and impair their sexual relationships with partners, resulting in diminished quality of life.

Breasts signify a woman's femininity, sexuality, and gender identity within Western cultures (Ruben & Tanenbaum, 2011; Ussher et al., 2012). Femininity in this manner, is defined as the quality of being female; it is socially constructed and varies according to culture (Ruben & Tanenbaum, 2011). The diagnosis of breast cancer has been portrayed as a cosmetic crisis for women as it is perceived as threatening to a woman's beauty (Ruben & Tanenbaum, 2011). It has been argued that there has been a disproportionate focus on cosmetic outcomes and reconstructive surgeries in the context of breast cancer (Ruben & Tanenbaum, 2011). The physical loss of a functional breast has been equated to a loss of attractiveness and sexuality in some women. This is due to perceptions of femininity and attractiveness that arise from breasts because of the sexual focus of Western societies on women and their bodies (Ruben & Tanenbaum, 2011). Scarring, deformity, or absence of a breast after surgical treatment can affect partner responses to a woman's breast and her self-perceptions of femininity and attractiveness (Bakewell & Volker, 2005; Katz, 2011). Undergoing a mastectomy is often equated with being or feeling less of a woman (Ussher et al., 2012). One research study conducted through feminist frameworks examined reasons why women choose to undergo breast reconstruction after breast cancer in Western society (Ruben & Tanenbaum, 2011). The authors found that women were made to feel like breast reconstruction was a natural step during breast cancer treatment following surgical interventions, in efforts to reduce

stigma associated with having a chronic illness and to conform to societal expectations for women's bodies (Ruben & Tanenbaum, 2011). Young women often report feelings of embarrassment and shame related to their bodies (Katz, 2011). Many women have reported difficulty viewing their bodies, and report a loss of dignity (Katz, 2011). Furthermore, women who have undergone a mastectomy report decreased tactile stimulation contributing to diminished sexual responses and arousal in contrast to those women who have undergone a lumpectomy (Bakewell & Volker, 2005).

Little research has been done on how CPM impacts woman's sexuality, with no studies to date examining sexuality exclusive to young women. Young women who have undergone CPM report a greater decline in sexual satisfaction than women who had breast conserving surgery or mastectomy with reconstruction (Fobair et al., 2006; Gilbert et al., 2010; Shell, 2008). Frost et al. (2005) identified that dissatisfaction with CPM correlated to diminished body image, with women (ages varied) indicating that they also experienced diminished sexual relationships and altered feelings of femininity. In another study examining sexuality and body image concerns in women (ages varied) with CBC who underwent CPM with immediate breast reconstruction, more than 50% of women reported problems with the appearances of scars; feeling less attractive and feminine (Unukovych et al., 2012). Similarly, in an integrative literature review examining body image and sexual changes following bilateral prophylactic mastectomy (BPM), McGaughey (2006) found that the prophylactic removal of both breasts in efforts to avoid future development of breast cancer in high risk women (ages varied) resulted in

decreased sexual pleasure and sense of sexual self, such as a loss of sensation in the breasts and the loss of their nipples. Furthermore, some of the women who underwent BPM reported an adverse effect on sexual relationships and a negative perception of sexual attractiveness (McGaughey, 2006).

Coping with changes in sexuality after breast cancer treatment. Breast reconstruction aims to restore body image and improve quality of life post mastectomy by preserving the shape of the breast area and maintaining symmetry (D'Souza, Darmanin & Fedorowicz, 2011). Women have chosen to undergo breast reconstruction after surgical treatments for breast cancer for reasons that include the desire for breast symmetry, avoidance of wearing prostheses, wanting to feel whole, and wanting to look normal (Ruben & Tanenbaum, 2011). Furthermore, some women had described their desire for breast reconstruction as a means of transforming one sick body into a healthy body after breast cancer (Ruben & Tanenbaum, 2011). Breast reconstruction involves rebuilding a woman's breast using tissue from other parts of her body (autologous reconstruction), or by implanting silicone or saline devices in the breast tissue (D'Souza et al., 2011). For some women, their nipples can be sparred during mastectomy and later sutured onto the rebuilt breast to create a natural looking breast (D'Souza et al., 2011). Silicone and saline implants may be implanted during immediate reconstruction if there is sufficient skin or soft tissue coverage provided by the skin flaps (D'Souza et al., 2011). If skin and soft tissue coverage is insufficient to cover the implant at the time of the mastectomy, tissue expanders placed under the pectoralis muscle can be used until

replacement with a permanent implant after the skin and soft tissue has stretched enough to cover the implant (D'Souza et al., 2011).

Breast reconstruction can be performed during the mastectomy (immediate reconstruction), or sometime later at the woman's request (delayed reconstruction) (D'Souza et al., 2011). Immediate reconstruction is often indicated for women who are unlikely to require additional radiation therapy (D'Souza et al., 2011). Immediate reconstruction has been reported to contributing to improved aesthetic outcomes for women as the breast envelope is preserved together with the inframammary fold creating a natural looking symmetrical breast (D'Souza et al., 2011). Delayed reconstruction is indicated for women who likely require post-mastectomy radiation therapy (D'Souza et al., 2011). Delayed reconstruction following radiation has been reported to result in tissue fibrosis in the chest wall and asymmetrical breasts contributing to negative self-esteem, body image and depression (D' Souza et al., 2011). Breast reconstruction can enhance some women's perceptions of femininity and improve body image. It does not preserve the potential for tactile stimulation, and studies indicate that women are not well informed about this adverse effect until they come to realize this during sexual experiences (Bakewell & Volker, 2005; Katz, 2011).

Review of the Juxtaposition of Medicine, Social Sciences, Nursing and Psychology on CPM

The literature presented in earlier sections within this literature review represent various perspectives and positions on CPM within the context of young women with

breast cancer. Medical literature describes how there is limited oncologic benefit in preventing future breast cancers or recurrences by performing CPM in women who do not possess BRCA I and II mutations, or possess a familial history of breast cancer (Davies et al., 2015; Lostumbo et al., 2010). Medical research studies have shown that surgical oncologists have discomfort with performing the procedure on women who do not have a deleterious BCRA mutation (Bellavelance et al., 2016). In most cases, CPM is not recommended as a surgical treatment option to prevent CBC in women who lack BRCA mutations and a family history, and the decision to undergo CPM is viewed as a personal choice by health care providers (Anderson et al., 2017; Bellavelance et al., 2016; Lostumbo et al., 2010). Reasons for choosing CPM cited in medical literature include a reduction in future CBC risk, prevention of metastatic disease, a desire for extending life and longevity, and alleviation of stress and anxiety (Anderson et al., 2017; Davies et al., 2015; Lostumbo et al., 2010; Rosenberg et al., 2013). Although diminished sexuality, and feelings of femininity and attractiveness have been identified in medical literature, the studies are mostly quantitative in nature, and do not explicitly examine these experiences neither before, or after undergoing CPM in young women with breast cancer. What is lacking in the current medical literature, is an in-depth analysis of the psychosocial reasons young women with breast cancer choose to undergo CPM. Generally, the consensus of the medical literature argues that CPM should only be reserved for women with breast cancer who possess BRCA mutations and/or a family history, without

exploring the unique risk of CBC and risk of more aggressive types of breast cancer occurring in young women specifically.

Feminist and sociological literature regarding women's decisions about their breast cancer care delve deeper into the meanings of the women's choices (Rees, 2017; Ruben & Tanenbaum, 2012). Breasts signify a woman's femininity, sexuality, and gender identity within Western cultures (Ruben & Tanenbaum, 2011; Ussher et al., 2012). The diagnosis of breast cancer has been portrayed as a cosmetic crisis for women as it is perceived as threatening to a woman's beauty (Ruben & Tanenbaum, 2011). From these perspectives, young women with breast cancer make choices about their health considering not only potential benefits to their physical health, but also potential benefits to their social and sexual well-being in the context of the societies expectations for women's bodies. For example, young women with unilateral breast cancer may choose to undergo CPM not only for longevity, but also for a higher probability of having bilateral breast reconstruction that results in favorable cosmetic results.

These perspectives are enhanced by those of other disciplines, such as nursing and psychology. The perspectives of psychology and nursing add considerable value to the literature, as they consider developmental tasks and past experiences of young women with breast cancer, and how that has shaped their decisions for treatment (Adams et al.; Campbell-Enns & Woodgate, 2015; Davies et al., 2015; Diaconu et al., 2014; Jerome-D'Emililia et al., 2015). These disciplines seek to understand women's reasons for choosing CPM by examining their concerns specifically related to achieving a healthy

young and middle adulthood. For example, the desire for longevity is examined explicitly in terms of the unique psychosocial challenges these young women face during breast cancer, such as finding a partner, having children, and raising a family. These perspectives acknowledge that while CPM may not be advised for all young women with breast cancer considering the beliefs about CBC risk from the view of the medical perspective, women must be supported and empowered to make their own decisions about their health that are consistent with their preferences and values, and will enhance quality of life in each domain (biological, social, cultural, psychological, emotional, and spiritual). A holistic focus is crucial in assuring attention to psychosocial needs and concerns that may be experienced within every stage of the cancer trajectory, including survivorship.

Summary

The diagnosis and treatment of breast cancer exerts significant stress on young women's sexuality, altering their body image and reducing their self-esteem. As there is limited research conducted on the effects of CPM on sexuality, and no research to date being conducted exclusively on young women with breast cancer who opted for CPM, it is essential that the effects of this risk reducing surgery on sexuality and quality of life be examined to provide quality care to these women and to assist them in making treatment related decisions. There is a need for approaches that elaborate the multi-dimensionality of the lived experience in young women's own voices.

Chapter 3: Research Methodology and Method of Human Science Phenomenology

For the proposed research study, I have used human science phenomenology to explore the meanings of sexuality in young women with breast cancer post CPM. In this chapter, I introduce the philosophical assumptions which underpin human science phenomenology. The relevance of human science phenomenology in examining sexuality in the study population is discussed. A detailed outline of the research method, population of interest, sample size and setting, data collection and data analysis techniques is provided. In addition, I discuss criteria for how methodological rigor was assured. Lastly, ethical issues and strategies related to the research study are discussed.

Evolution of Human Science Phenomenology

In this section, the methodological roots of human science phenomenology and its relevance to health research is discussed.

Methodological Roots of Human Science Phenomenology

Methodology is defined as the theory, or philosophical underpinnings, assumptions, and characteristics of the research paradigm (van Manen, 1990). The methodology underpinning this qualitative research study is human science phenomenology. Human science phenomenology is both a philosophy and an inductive and dynamic qualitative research method (Reiners, 2012; Wojnar & Swanson, 2007). As a philosophy, phenomenology uncovers rich perspectives from ongoing intellectual dialogues (Melnyk & Fineout-Overholt, 2011). The philosophy of phenomenology arose through the naturalistic paradigm (reality is presumed to be based on individual and subjective

realities) rather than the tenets of empiricism and reductionism consistent with the positivist paradigm (Finlay, 2009; Reiners, 2012). As a method, human science phenomenology is a "systematic attempt to uncover the structure, the internal meaning structures, of lived experience" (van Manen, 1990, p. 10). It is the study of the lifeworld, defined as the world as we experience it pre-reflectively rather than as we conceptualize or reflect on it (van Manen, 1990).

Historical Evolution of Human Science Phenomenology

Human science phenomenology developed by Max van Manen (1990) is derived from the founding authors of phenomenology - Edmund Husserl and Martin Heidegger. Their work will be described to demonstrate the origins of human science phenomenology.

Husserl (Descriptive Phenomenology). Descriptive phenomenology was founded by Edmund Husserl (1859-1938), a German philosopher and mathematician, who believed consciousness to be the condition of all human experience (Lopez & Willis, 2004; Wojnar & Swanson, 2007). Descriptive phenomenology aims to unravel thick, rich descriptions of universal essences, which are considered representative of the world in which a person lives (Lopez & Willis, 2004; Wojnar & Swanson, 2007). Husserl believed the lived experience, or lifeworld, was described as understandings about life's meanings that are present outside of a person's consciousness (Lopez & Willis, 2004; Melnyk & Fineout-Overholt, 2011). He emphasized the importance of transcendental consciousness (remaining open to the reality of another's experience) in order to discover meaning

attributed to individual experiences (Reiners, 2012; Trinidad, 2007; Wojnar & Swanson, 2007). Husserl developed phenomenology using the concept of intentionality (that which directs a person's awareness or consciousness of an event or object) and the meaning of the lived experience from the person's view point (Reiners, 2012; Wojnar & Swanson, 2007). In descriptive phenomenology, human beings are viewed as free agents responsible for influencing their environments (Wojnar & Swanson, 2007). Therefore, the critical question for Husserl was: What do we know as persons? (Reiner, 2012). Husserl believed that the meaning of the lived experience could be discovered through one-to-one transactions involving attentive listening, interaction, and observation between the researcher and research participant (Wojnar & Swanson, 2007).

Husserl sought to explain how to overcome personal biases which threaten attainment of pure consciousness (Melnyk & Fineout-Overholt, 2011; Wojnar & Swanson, 2007). For a researcher to suspend their own lived reality, which is necessary to describe the phenomena of interest in a pure and universal sense, one must achieve transcendental subjectivity (neutrality) (Wojnar & Swanson, 2007). Transcendental subjectivity is achieved through bracketing, a practice in which one consciously and actively suspends personal bias, beliefs, experiential knowledge, and opinions about phenomenon to refrain from influencing the description of the phenomena under investigation (Wojnar & Swanson, 2007). Through bracketing, insight into common features of any lived experience can be discovered (Lopez & Willis, 2004; Wojnar & Swanson, 2007). The process of bracketing includes the following steps: 1) inspection of

the phenomena through separation of the phenomena from the world, 2) dissection of the phenomena to discern its structure, 3) defining and analyzing it, and 4) abandoning preconceptions so that the researcher does not hold any preconceived ideas during engagement with the participant and analysis of the descriptions (Wojnar & Swanson, 2007). Bracketing can occur by using field notes as a reflective diary to document the researcher's observations, assumptions, and confusions, seeking critique from experts in the research area of interest or descriptive method, and reflecting on the influence that personal bias can play on the description of the phenomena (Wojnar & Swanson, 2007).

Heidegger (Interpretive Phenomenology). A student of Husserl, Martin Heidegger (1889-1976), believed that human beings are hermeneutic, or interpretive, and capable of finding meaning in their own lives (Lopez & Willis, 2004; Reiner, 2012; Wojnar & Swanson, 2007). He studied how individuals are present in the world, rather than knowing the world (Lopez & Willis, 2004; Reiner, 2012).

Interpretive phenomenology is based on the perspective that understanding of persons does not occur in isolation of their societal, cultural, and political contexts (Wojnar & Swanson, 2007). For Heidegger, the critical question was: What is being? (Lopez & Willis, 2004; Reiner, 2012). The concept of the human way of being-in-the-world (*dasein*) is used to emphasize that individuals cannot abstract themselves from the various contexts of their lives that give meaning to lived experiences (Lopez & Willis, 2004). It is the basis of human existence and can be understood as the interconnectedness

and interdependence of human relationships (Pascal, Johnson, Dore & Trainor, 2010; Wojnar & Swanson, 2007).

Being-in-the-world includes a holistic and existential exploration of the phenomena as temporal (lived time), spatial (lived space), corporeal (lived body) and relational (lived human relation) (Pascal et al., 2010; Tuohy et al., 2013). The assumptions of being-in-the-world and presence in situations form the basis of pre-understanding, which consists of fore-having, fore-sight, and fore-conception (Tuohy et al., 2013; Wojnar & Swanson, 2007). Fore-having ascertains that persons come to a situation with practical familiarity or background practices from their own world that makes interpretation possible (Wojnar & Swanson, 2007). Fore-sight refers to the sociocultural background that provides a view point from which to make an interpretation (Wojnar & Swanson, 2007). Fore-conception refers to sociocultural background that provides a reference for anticipation of what may be uncovered in the research study (Wojnar & Swanson, 2007). Fore-structure (prior awareness) is what is known or understood before interpretations and it stems from past experiences (Tuohy et al., 2013; Wojnar & Swanson, 2007).

Prior to conducting an inquiry of phenomena or experience of interest, the researcher must reflect on their past experiences and preconception of the phenomena being investigated to ensure that the interpretive process clearly assesses the experiences of the participant (Lopez & Willis, 2004; Wojnar & Swanson, 2007; Tuohy et al., 2013). Heidegger defines the interpretive process as circular, shifting back and forth between the

whole and its parts, and between the investigator's pre-understanding and what was unveiled during the investigation (Lopez & Willis, 2004; Wojnar & Swanson, 2007). This process is termed co-constitutionality (Wojnar & Swanson, 2007). Interpretive phenomenology aims to discover the participant's meanings from a mix of the researcher's understanding of the phenomenon and information communicated by the participants (Lopez & Willis, 2004; Wojnar & Swanson, 2007).

Heidegger assumed that human existence is more than human consciousness and knowledge, as understanding of the everyday world is derived from the person's interpretation (Reiner, 2012). The focus of interpretive phenomenology is to explore the lived experience and to recognize that individual's realities are influenced by their relationships and surrounding environments (Reiner, 2012; Tuohy et al., 2013). Interpretive phenomenology recognizes that the researcher is inseparable from assumptions and preconceptions about the phenomena of interest, and must be acknowledged and integrated into the study findings (Reiner, 2012). Thus, bracketing is not warranted in interpretive phenomenology (Reiner, 2012; Tuohy et al., 2013).

van Manen's Human Science Phenomenology. van Manen (1990)'s approach to phenomenology incorporates Husserl's descriptive phenomenology focusing on the study of the world before reflection. He also argues that studying the world involves interpretation, which is consistent with Heidegger's interpretive phenomenology (Dowling, 2007). Using both descriptive and interpretive phenomenology, van Manen suggests that when description is mediated by expression (non-verbal gestures, actions, or

text, etc.), a more in-depth element of interpretation is involved (Finlay, 2009). However, van Manen identifies that interpretation extends beyond pointing to something; it identifies the meaning in something by imposing an external framework (Finlay, 2009). In contrast to Husserl's descriptive phenomenology, van Manen does not embrace the need for bracketing, and argues that if researchers attempt to forget what is already known, the presupposition will persist in their reflections (Dowling, 2007).

Phenomenological research aims to gain a deeper understanding of the nature of meaning of everyday experiences (van Manen, 1990). As such, phenomenology can also be described as the study of meaning structures of a phenomenon, or essences, intuited through the description of lived experiences (van Manen, 1990; Melnyk & Fineout-Overholt, 2011). Essences are internal meaning structures of a phenomenon grasped through the study of the lived human experience (van Manen, 1990). Essences can only be intuited through the study of instances as they are encountered in the lived experience (van Manen, 1990). The lived experiences under study in phenomenology are everyday experiences that are described in terms of how the experience felt, or what is was like having an experience, rather than how the experience was conceptualized (Melnyk & Fineout-Overholt, 2011).

Husserl's four existentials derived from being in the world (temporality, corporeality, spatiality, and relationality) provide guidance for researchers on phenomenological writing (Dowling, 2007). The four existentials signify a collaboration of the parts of human existence that contribute to whole concepts of human reality and

pre-understanding in hermeneutic study (Dowling, 2007). Lived space, or spatiality is a category for inquiring into the ways we experience spatial dimensions of our day-to-day existence (Dowling, 2007). The existential of lived body, or corporeality, refers to the fact that we are always present within the world and cannot be separated from it (Dowling, 2007). The existential of lived time, or temporality refers to time as being subjective in nature as opposed to objective, or clock time (Dowling, 2007). The last existential, lived human relation, or relationality, refers to the lived relation we maintain with others in the interpersonal space that we share with them (Dowling, 2007).

Relevance of Human Science Phenomenology for This Study

Human science phenomenologists believe human experiences to be more complex than a single description (van Manen, 1990). van Manen's approach is different from other phenomenologists as it not only describes the lived experience, but describes how the researcher comes to interpret the meaning of the lived experience (Finlay, 2009; van Manen, 1990). van Manen suggests that when the description of the experience is mediated by expression, non-verbal behavior, artwork, written text, and actions, then a rich interpretation of the lived experience emerges (Finlay, 2009).

In health research, the phenomena of interest related to states of illness includes how a person experiences a phenomenon such as healing, caring, hope, trust, sexuality, or wholeness (Melnyk & Fineout-Overholt, 2011; Wojnar & Swanson, 2007). It is through discovery of these meanings that health care providers design holistic interventions to best meet the needs of clients, families, and communities and enhance quality of life

(Wojnar & Swanson, 2007). Due to its unveiling nature of human experiences, human science phenomenology is well suited to examine meaning structures embedded in the lived experiences of sexuality by young women with breast cancer who have opted to undergo CPM. Given this, human science phenomenology adopted as a research methodology will discover meanings of sexuality embedded in thoughts, feelings, values, emotions, purposes, and actions of young women as they make sense of their sexuality post CPM.

Method

The method is the theoretical and practical procedures for conducting a research study (van Manen, 1990; Melnyk & Fineout-Overholt, 2011). The following section presents the research method consistent with human science phenomenology used in this study to guide selection of participants and collection and analysis of data.

Design. Qualitative research designs, although low on the hierarchal scale of the level of evidence, are well suited to examine research questions regarding the "whatness" of something, especially when little is known about a topic (Melnyk & Fineout-Overholt, 2011; van Manen, 1990, p.33). Qualitative research methods such as phenomenology can contribute to the body of knowledge by expanding what is known about human experiences as they are lived (Melnyk & Fineout-Overholt, 2011; van Manen, 1990). As such, the qualitative research design human sciences phenomenology was chosen to examine the experiences and meanings of sexuality as experienced by young women with breast cancer post CPM.

Sample selection and size. In qualitative research, it is necessary to have a sample that is representative of the population of interest (Melnyk & Fineout-Overholt, 2011). Purposive sampling was used to intentionally select participants who would provide perspectives relevant to the research question (Melnyk & Fineout-Overholt, 2011). Only participants who have lived the experience were included in the study in keeping with principles of human science phenomenology (Melnyk & Fineout-Overholt, 2011; van Manen, 1990). Given that the diagnosis of breast cancer is difficult for women, only young women who were at least six months' post diagnosis were recruited for this study to allow them time to cope with their diagnosis. Women who were aged 20-44 years at the time of CPM were specifically chosen as this age range is consistent with the Canadian Cancer Society's definition of young women (CCS, 2014). Women who were over the age of 44 years at the time of the interview were eligible to participate, if they had undergone CPM as a young woman (20-44 years). This way they could reflect on their experiences of sexuality following CPM during that time.

Women who have had breast reconstruction that occurred following CPM were eligible to participate. Both women who are at high risk for developing unaffected breast cancer (e.g., family cancer history or mutation in breast cancer genes) and those who are not at high risk were eligible for study participation. In addition, participants could read, write and speak English. Initially, the study was restricted to women living within Atlantic Canada. To facilitate recruitment, this eligibility criterion was broadened to include women who resided anywhere in Canada. After inclusion and exclusion criteria

had been applied, a purposive sample of seven women who were diagnosed with unilateral breast cancer and who opted to have a CPM performed during their life as a young woman (aged 20-44 years) were recruited for this study.

In qualitative research, there are no statistical procedures, such as power analyses to determine appropriate sample size (Melnyk & Fineout-Overholt, 2011). Therefore, it is essential to choose a sample size that elicited rich descriptions of women's experiences of sexuality. It was anticipated that 6-8 women were needed to achieve saturation (i.e., no new data emerges) (Melnyk & Fineout-Overholt, 2011).

Participant recruitment. To facilitate participant recruitment, a variety of methods were employed. Participant recruitment occurred by posting advertisements in hospitals within the Horizon Health Network. I worked with a Clinical Nurse Specialists (CNS) working in cancer care within the Horizon Health Network to assist with recruitment of participants from her practice area. To assist in this process, the CNS was provided with an in-depth information letter regarding study purpose, eligibility criteria, method, and relevance to cancer care. Recruitment assistance was also sought from cancer organizations including the Canadian Cancer Society (CCS), Young Adult Cancer Canada (YACC) and ReThink Breast Cancer, and cancer support groups such as "Look Good Feel Better" and "Bosom Buddies of Nova Scotia". Lastly, social media outlets such as Facebook were used to advertise this research study.

Recruitment was ongoing until sample size and data saturation had been reached.

The seven women who participated in this research study were recruited through YACC, ReThink Breast Cancer, and the New Brunswick Breast and Women's Cancer Partnership. Two women were recruited via the snowball method. Snowballing is a sampling method in which existing study participants recruit additional participants through word of mouth (Melnyk & Fineout-Overholt, 2011).

Data collection. A demographic form was used to collect information about participants such as age, marital status, cancer history and risk, and reproductive history (see Appendix C). This form was created for this study with variables chosen to describe the context of the participants. The demographic form took approximately five minutes to complete.

Interviews are used in human science phenomenology to delve deeply into the lived experience and meanings attributed to a phenomenon (Melnyk & Fineout-Overholt, 2011; van Manen, 1990). For this study, I conducted semi-structured, open-ended interviews to allow participants to express their thoughts, memories, reflections, and ideas they deemed relevant and meaningful to the lived experience and their perceptions of self as sexual beings (Melynk & Fineout-Overholt, 2011).

Consistent with van Manen's (1990) human science phenomenology, interview questions were constructed to examine meanings of sexuality post CPM as they related to lived body, lived time, lived space, and lived relations (see Interview Guide in Appendix D). For example, to capture the lived body, I posed questions such as: What changes have occurred in your body because of having a CPM? How did you feel about these changes?

Women who have had delayed breast reconstruction will be asked to reflect upon their past experiences of sexuality between the time of the contralateral prophylactic mastectomy and breast reconstruction to gain a sense of what the experience of sexuality was like for these women.

Interviews questions were phrased in language appropriate to the participant's understanding of their disease (i.e., using lay terms when appropriate and avoiding use of complicated medical terms). Probing questions were used to assist participants to focus on specific events and situations. They were open enough for participants to develop the conversation in whichever way was most relevant for them. Additional therapeutic techniques such as silence and minimal cues (e.g., head nodding, saying "go on") were used to encourage participants in their discussion (Egan, 2013). Participants were asked to provide examples of relevant situations and experiences (van Manen, 1990). I used paraphrasing, summarizing and empathic highlights to confirm my understanding of participants' thoughts and feelings.

Interviews took approximately one hour to complete. A follow-up interview was offered to participants to allow expansion of their ideas and thoughts, and as means to validate the data and emerging themes, however, follow up interviews were not needed. I conducted the interviews at an office on the University of New Brunswick campus, as well as in participant's home as per their request. For interviews that could not be completed in person, the internet program Skype was used. For these interviews,

participants had to have had access to a computer with Internet as well as a web camera. Interviews were digitally recorded and transcribed verbatim.

Another source of data used in this study was field notes. Field notes are observational records of nonverbal cues, behaviors and events that can be used to enhance data findings and contribute to a rich description of the experience (Melynk & Fineout-Overholt, 2011; Sloan & Bowe, 2014). More specifically, I used field notes to document and monitor participant behaviors, nonverbal cues, records of events, reminders to explore a concept further, emerging patterns noted from the data, and identification of personal biases, attitudes, beliefs and values related to sexuality throughout the interview process (van Manen, 1990). For example, before every interview, I would reflect on my own values and beliefs and note any assumptions I held about the experiences of sexuality in the context of breast cancer and CPM prior to engaging in discussion with the participants to ensure unbiased analysis of their experiences. Furthermore, during the interview process, I would note facial expressions, tone, and body language of the participants when discussing personal experiences of sexuality in the context of the four existentials. Below is short excerpt from a field note written during an interview undertaken with one of the participants.

> Discussing the changes to her physical body after CPM…gaze shifts from me, down to the floor discussing her feelings of grief following losing her breasts after CPM….voice trails off. Changes discussion to diagnosis…

Probe: asked to elaborate on what was meant by feelings of grief post CPM.

Describes how she grieves her the look of her old body (blonde hair, two breasts she felt were perfect for her)…begins to tear up. The interview is paused

Field notes taken during the interview process were brief in nature and served only to cue myself to return to certain points of the discussion for further examination and clarification. This is due to realizing that during the first interview, one women appeared guarded in her responses as she noted documentation of some aspects of her experiences, and not others, perhaps feeling that these undocumented experiences were less important. To facilitate and open and unguarded discussion, more detailed documentation of field notes occurred immediately following the interview.

Data analysis. In human science phenomenological research, data analysis occurs concurrently with data collection, meaning that the researcher is attentive to emerging themes beginning with data collection (van Manen, 1990). Sensitivity, or full immersion into the data, assists in identification of subtle cues in text that leads to meanings of lived experiences (van Manen, 1990). I listened to the interviews multiple times to achieve sensitivity becoming fully immersed in the data (van Manen, 1990). I reviewed the interview transcripts using van Manen's selective highlighting approach. This approach involves selecting and highlighting sentences or groups of sentences that are thematic of the lived experiences of participants (van Manen, 1990). For example, when a sentences or paragraphs described how it felt to engage in sexual intimacy following CPM, those sections were highlighted and examined for commonalities that represented the

existential of lived body. Textual data was reduced until essential themes emerge. Essential themes of the experience exist if it "makes a some-'thing' what it is—and without which it could not be what it is" (van Manen, 1990, p. 10). The following excerpt is an example of the selecting and highlighting approach used for examining lived body.

> That was uh....that was terrifying. Umm...the first...when I kind of woke up from surgery, like I went into surgery, you know I made jokes of it, I was that person that tried to make it light so I didn't cry and like told my husband to kiss them goodbye, that it was the last time he was going to see them, but when I woke up I really didn't...like of course you are in a haze of all the anesthetic and everything but then when the nurse came in to change my dressing and I looked down at my chest it was horrifying, just horrifying. They had put, I call them the Frankenstein staples, they were just all the way across my chest and it was hard to look at a body that I was looking at for 33 years, like I'm not going to lie, I loved my breasts, they were the perfect size for me, they never gave me any trouble, they fed my son for five months and then they were gone so it was hard, it was really hard to look at definitely. The nurse took off the bandages and I sobbed for quite some time but it was a decision that had to be done, but you definitely grieve; you grieve what you looked like before and you realize how lucky you actually had it before.

Emergent themes representative of young women's experiences of sexuality following contralateral prophylactic mastectomy were captured in terms of essences, or meaning structures for a rich and thick description of the lived experience (van Manen,

1990). This process involved writing and re-writing the themes in different ways to develop the interpretation (van Manen, 1990). Direct quotes from participants were used to illustrate how the description of the participants' lived experience of sexuality developed into themes (van Manen, 1990).

In phenomenology, a key step in data analysis is engagement of the researcher in a process called phenomenological reduction (Finlay, 2014; van Manen, 1990). van Manen (1990) describes phenomenological reduction as the researcher engaging in reflection of their own pre-understandings, frameworks, and biases as each relates to psychological, political, and ideological motivation and the nature of the research question (van Manen, 1990). This reflection helps the researcher remain open in a conversational relation with the phenomena under study (van Manen, 1990). van Manen describes phenomenological reduction as the researcher overcoming personal feelings, preferences, inclinations, or expectations that may persuade the researcher to come to a premature, wishful, or one-sided understanding of the experience; failing to discover a phenomenon as it is lived through (van Manen, 1990). To ensure unbiased and mature descriptions of the lived experience through discovered meanings of sexuality post contralateral prophylactic mastectomy in young women with breast cancer, I reflected on personal opinions, expectations, attitudes, and beliefs about sexuality, and what it may mean for young women with breast cancer after mastectomy. For example, prior to entering the interview, I would note any expectations I had about the how the interview may unfold based on information the women had provided during the recruitment process (i.e., women who

were married with children may experience sexuality different from single women without children, etc.). I accepted what participants share about their experiences to be the truth in absence of moral judgment by focusing on the meaning of the situation as it is described by their experiences (Finlay, 2011; Finlay, 2014). My personal biases, judgments and presumptions related to the research question were documented before the interviews take place, before and during the interview using field notes, and after the interviews to not influence the interpretation of the emerging themes (van Manen, 1990). For example, before interviewing Alexandra, my first participant, I documented how I felt about my own sexuality, and how losing my breasts could impact my self-perceptions of attractiveness and femininity. I documented my personal beliefs surrounding Western society's views and expectations for women's bodies, as well as my own beliefs about what breasts signify for women (for example, nourishment for infants and toddlers, and a source of sexual pleasure through stimulation).

Descriptive analyses, such as frequency and mean, was used to describe the demographic data (Sloan & Bowe, 2014). The demographic data contributed to research findings by depicting the characteristics of the sample in terms of disease, life stage, and treatment.

Methodological Rigor and Trustworthiness

To ensure methodological rigor of this qualitative study, I used Lincoln and Guba's (1985) four aspects of trustworthiness: credibility, dependability, confirmability, and transferability. Techniques for enhancing methodological rigor in relation to Lincoln

and Guba's (1985) four criteria are discussed in the following section. Assurance of methodological rigor is important in qualitative research as it contributes to authenticity of results (Melynk & Fineout-Overholt, 2011).

Credibility. Credibility refers to confidence in the truth of the research findings (Lincoln & Guba, 1985). For this study, I remained open to the data as it was obtained and limited my influence on the development of the interpretation of themes by documentation of my biases, beliefs and presumptions before data collection, during the interview process via the use of field notes, and following data collection (Lincoln & Guba, 1985; Melynk & Fineout-Overholt, 2011; van Manen, 1990). For example, after interviewing Alexandra, I reflected on my own presumptions about society's views and expectations for women's bodies, to ensure my own perceptions did not influence the meaning Alexandra attributed to her experiences of sexuality within the context of Western culture. Furthermore, achieving data saturation is another way to demonstrate the credibility of the data. In phenomenological research, a sample size of six to eight participants is generally sufficient to reach data saturation and to elicit thick and meaningful descriptions of the lived experience (Melynk & Fineout-Overholt, 2011). I used member checking to demonstrate that the findings and interpretations of the data reflected participant experiences (Lincoln & Guba, 1985; Melynk & Fineout-Overholt, 2011). I asked participants during and after the interview if I had captured their experiences accurately by restating what I had heard them describe in the interview. Debriefing and discussions with my supervisor allowed us to jointly develop

interpretations of meanings attributed to women's sexuality post contralateral prophylactic mastectomy (Lincoln & Guba, 1985; Melynk & Fineout-Overholt, 2011).

Transferability. Transferability is achieved when the findings elicited from the study are meaningful to others in a similar situation (Lincoln & Guba, 1985). It is represented by how participants make sense of their experiences, and how effective the researcher conveys the findings and the assumptions of the research study (Melynk & Fineout-Overholt, 2011). I assured transferability by ensuring that study findings reflect participants' experiences of sexuality by engaging in peer review with my supervisor and by verifying constructed themes and meanings of sexuality with study participants as they emerged in the interview process, and via email following data analysis.

Dependability. Dependability refers to the ability of the research study to be replicated to produce similar results (Lincoln & Guba, 1985). To achieve this criterion, I constructed an audit trail to maintain record of information such as the recruitment processes, sample characteristics, interview setting, detailed methodology, documentation of personal reflections, and analyses (Lincoln & Guba, 1985; Melynk & Fineout-Overholt, 2011).

Confirmability. Confirmability is the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest (Lincoln & Guba, 1985). I achieved confirmability using direct quotes from participants, member checking, field notes, and adhering strictly to the methodological process (Melynk & Fineout-Overholt, 2011).

Ethics

In the following section, I discuss ethical considerations and anticipated issues pertaining to the proposed research study. I outline strategies that were used in seeking ethical approval.

Ethical approval. I sought ethical approval to conduct this research project through the Research Ethics Board at the University of New Brunswick and the ethics board at Horizon Health Network. Ethical approval was granted through both research ethics boards. Two important amendments were made through the Research Ethics Board at the University of New Brunswick to facilitate study recruitment. First, young women who resided anywhere in Canada were permitted to participate. A change from previous eligibility criteria, that allowed young women from outside the Atlantic provinces to participate. Secondly, women who had undergone CPM as a young woman were permitted to participate in the study, even if they were greater than 44 years of age at the time of interview, as they were able to provide rich descriptions of their experiences as young women upon personal reflection.

Risks and benefits. Autonomy is an ethical principle in which individuals are fully capable of making their own choices and demonstrate competence in understanding risks, benefits, and personal and legal rights in situations. Detailed information about the study was provided (see Appendix A for the information letter). Participant autonomy was achieved through informed verbal and written consent (see Appendix B for consent form). I encouraged the women to ask me questions about the study. I ensured that

participants fully understood that their participation in the study was entirely voluntary and that they could withdraw from the study at any point in time, without penalty. Participants were advised that their participation in the research study did not affect their relationship with the University of New Brunswick and/or Horizon Health Network.

Potential risks associated with participation in the study, such as emotional distress related to discussing sensitive topics of cancer and sexuality were discussed with participants. Three of the participants became emotional describing their experiences. The interviews were immediately stopped, and the women were encouraged to take time to gather their thoughts and reflect upon their feelings before moving forward with the interview. None of the women wished to be referred to their family practitioner or oncologist for supportive care or counselling following the interviews. After the interview, follow up contact was made within participants 24-72 hours to provide them the opportunity to discuss any questions, concerns, feelings or emotions that were provoked by the interview. Participants were made aware that their participation in this study may benefit nurses and other health care providers by enhancing knowledge related to sexuality and cancer in the population of interest and contributing to improved quality care in oncology. A written record of personal interviews and summary of the research findings were made available to study participants.

Privacy and confidentiality. I ensured ethical responsibility to participants by communicating their right to confidentiality, anonymity and privacy. I assured these rights to study participants by keeping all files in a locked file cabinet at my home office,

and by removing all identifying information from study documents and replacing participant's names with a pseudonym on all files. Only the researcher and the researcher's supervisor had access to participant files. Any documents kept electronically (e.g., interview transcripts) were password protected.

Summary

When little research has been conducted in an area such as the effects CPM on sexuality in young women with unilateral breast cancer, qualitative research designs are well suited for exploration of the phenomenon. Because of its focus on revealing the nature of human experiences in the world, phenomenological research can be used effectively to delve deeply into the human experience that is lived and shared among young women post CPM. Using phenomenological research methodology, I was able to uncover the meanings of sexuality embedded in thoughts, feelings, values, emotions, purposes, and actions of young women as they made sense of their sexuality post CPM.

Chapter Four: Findings

In this chapter, I present the findings of the study. First, a description of the participants by demographic data is presented. This is followed by a description of the essence of the lived experience of sexuality post CPM for young women with breast cancer and themes which contribute to this essence. Through phenomenological analysis, the essence is described for these young women with breast cancer as "My body is scarred, but for that I am stronger".

Demographics

Seven women of Caucasian ethnicity participated in this study. They had a mean age of 40 years at the time of the interview, ranging from 31 to 52 years in age. All the women had achieved some level of post-secondary education (Table 1). Most of the women were married at the time of the interview, working full time and had children. The women resided in New Brunswick, Newfoundland, Quebec and British Columbia. See Table 1 for the summary of participant demographic data.

Table 1

Participant Demographics

Characteristic	Number (%)
Age at interview (years)	
20-44	6 (85.7)
>44	1 (14.3)
Marital status	
Married	5 (71.4)
Single	1 (14.3)
Common law	1 (14.3)
Children	
Yes	5 (71.4)
No	2 (28.6)
Planned on having future children	
Yes	1 (14.3)
No	6 (85.7)
Area of residence	
Urban	3 (42.8)
Suburban	2 (28.6)
Rural	2 (28.6)
Ethnicity	
Caucasian	7 (100.0)
Education	
University	5 (71.4)
College	2 (28.6)
Employment	
Full time	4 (57.1)
Part time	2 (28.6)
Long term disability	1 (14.3)

The mean age of the women at the time of cancer diagnosis was 35 years, with a range of 30 to 41. All women were diagnosed with breast cancer (either triple negative breast cancer or invasive ductal carcinoma) in one breast. All had undergone CPM, either at the same time as the removal of the cancerous breast or after having the mastectomy. All the women had undergone CPM during their life as young women (22-44 years of

age), and reflected on their experiences of sexuality post CPM during that time. In addition to the mastectomy, all women had some combination of chemotherapy, radiation, and hormonal therapy during their treatment. Three of the women had breast reconstruction. One woman had immediate delayed reconstruction. This refers to her having had saline implants inserted during the time of the mastectomies. She continues to have saline repeated injections of saline placed into the breasts, until appropriate size and symmetry is achieved. The other two women underwent delayed breast reconstruction. See Table 2 for a summary of participants' health history.

Table 2

Breast cancer history, treatment and breast reconstruction

Characteristic	Number (%)
Age at diagnosis and CPM (years)	
20-44	7 (100.0)
Type of breast cancer	
Triple negative	2 (28.6)
Invasive ductal carcinoma	5 (71.4)
Stage	
Stage 1	1 (14.3)
Stage 3	5 (71.4)
Not sure	1 (14.3)
Surgical treatment	
Lumpectomy and mastectomy	1 (14.3)
Mastectomy only	6 (85.7)
Chemotherapy	
Neo-adjuvant	2 (28.6)
Adjuvant	4 (57.1)
No chemotherapy	1 (14.3)
Radiation	
Adjuvant	5 (71.4)
No radiation	2 (28.6)
Endocrine/Biological therapy	
Tamoxifen, Herceptin, Letrozole, or Zoladex	5 (71.4)
No treatment	2 (28.6)
Other treatment	
Bisphosphonate therapy	2 (28.6)
No treatment	
Breast reconstruction	
2 stage reconstruction	2 (28.6)
Delayed reconstruction	1 (14.3)
No reconstruction	4 (57.1)

Of the seven women, four had a known family history of breast cancer. One woman had first, second and third degree maternal relatives who were diagnosed with breast cancer, and a first degree relative who was diagnosed with ovarian cancer. This

participant's family was identified as a cluster lineage for both breast and ovarian cancer. The other two women who had a maternal family history of breast cancer had second and third degree relatives who were diagnosed with breast cancer. One woman had a second degree paternal relative who had breast cancer. Most of the women had chosen to undergo genetic testing for BRCA I and BRCA II genetic mutations, among other genetic mutations. Only one woman who was tested had a positive genetic mutation located in the BRCA II gene, and this was the woman who has the familial cluster of breast and ovarian cancer. See Table 3 for participants' family and genetic history.

Table 3

Family history and genetic predisposition to developing breast cancer

Characteristic	Number (%)
Family history of breast cancer	
1st, 2nd or 3rd degree maternal relative	3 (42.85)
2nd degree paternal relative	1 (14.3)
No family history	3 (42.85)
Genetic testing (BRCA I and BRCA II)	
Yes	5 (71.4)
No	1 (14.3)
On waiting list	1 (14.3)
Results of genetic testing (BRCA I and BRCA II)	
Positive	1 (20)
Negative	3 (60)
Inconclusive	1 (20)

Findings

The essence of the seven young women's lived experiences of sexuality post CPM is presented in the following section followed by a description of the three themes that emerged from the interviews. Unveiling the description of the essence answers the research questions: 1) What meanings do young women with breast cancer ascribe to their experiences post CPM 2) What meanings do young women with breast cancer ascribe to their sexuality post CPM?

The Essence of Young Women's Lived Experiences of Sexuality post CPM

The essence of these young women's lived experience of sexuality post CPM is defined as "My body is scarred, but for that I am stronger". For these women, breast cancer had scarred their body physically, but strengthened them emotionally. Breast cancer treatments, such as surgery, chemotherapy, radiation and endocrine therapy had resulted in physical changes that negatively affected the way they saw themselves as desirable young women. Furthermore, the diagnosis of breast cancer resulted in psychological distress as the women feared for their lives, and tormented them with anxiety and concern related to the well-being of their families if they did not survive. Despite these challenges, these women rose above their breast cancer diagnoses and treatment adversities. They became empowered, embracing their inner strength and courage, not allowing themselves to be defined by their illness. The following sections describe how breast cancer and its treatment scarred their bodies physically, and how they came to embrace them.

Although the focus of this study examined the effects of CPM on sexuality in young women with breast cancer, other treatment modalities were described as negatively impacting sexuality and quality of life for these women. Radiation therapy to their breasts and chest walls caused burning and long lasting pain, limiting the amount of tactile stimulation some of these women could endure when being intimate with partners. It also resulted in scars, which some of the women felt uncomfortable exposing during times of intimacy. Chemotherapy resulted in alopecia (loss of hair, eye lashes and eye brows) during treatment, all contributing to negative self-perceptions of femininity and attractiveness. In terms of sexual intimacy and pleasure, chemotherapy resulted in vaginal dryness and atrophy causing dyspareunia. Both chemotherapy and radiation therapy resulted in fatigue and loss of energy for these women, making it difficult to engage in intimacy with their partners. Lastly, endocrine therapy resulted in weight gain, which diminished sexual desire.

Undergoing CPM resulted in many physical changes to the women's bodies that negatively affected how they perceived themselves as women within their intimate sexual relationships, and within their social environments. For them, a "normal" woman is one who has symmetrical breasts in terms of size and shape, cleavage, intact nipples, smooth skin that is not burned or scarred, and has no catheter lines. As Deanna (names changed to protect identity of participants), 47-years-old, said: "I don't have any cleavage right, so in my mind I don't look normal, whatever normal is."

Having two breasts made the women feel feminine and desirable, and the subsequent loss of their breasts negatively affected the way they perceived themselves as sexual beings. Most of the women did not anticipate how CPM might impact their body image and sexual satisfaction. Alexandra, 34-years-old, shared:

> It's hard, it really is, like not only have you lost your breasts, which were a very huge part of how women are sexualized and that's it, I mean they really are part of how you feel feminine and how you feel sexual, and how men see women; breasts are a huge part of it…

In the above quote, Alexandra referred to society's sexual focus on women's bodies, and how having two breasts associates them with their sexual identity, particularity in the eyes of men. She describes how this view has negatively impacted the way she views herself feminine and sexual.

In contrast, some women did not initially disclose that undergoing CPM had impacted their sexuality. They described themselves as being strong women who were not easily distracted by societal expectations of femininity and attractiveness. However, as the interviews continued to unfold, insecurities about how their bodies would be perceived by others emerged. Most of the women felt their chests without breasts made them appear less feminine and attractive.

According to all the women in this study, CPM scarred their bodies. It left incision scars where there once were breasts. It resulted in diminished or absent sensation to their chest wall. For some, removal of the muscle and tissue produced chest wall

tenderness and discomfort that did not recede following CPM. Breast reconstruction was disappointing for some women. They had breast reconstruction to make them appear more like "normal" women, but the outcomes were not what the women anticipated. Becky, 30-years old, talked about her mastectomy scars:

> I'm cool with the one in my armpit…I'm cool with the other scar that I have from the lumpectomy but that's been cut out along with my nipple when they did the mastectomy, but like so far I still have the scars taped up to get them to heal nice and flat and so anytime that I take the tape off I'm just like eh, I don't like these, you know it should be nice smooth skin and nipples and areolas but all I've got are these lines, kind of jagged lines across the front of my chest, it's not right.

As Becky describes, her experience, breast reconstruction did not result in "normal" looking breasts due to the skin changes and scars to her breasts.

The most common way that most women coped with their scarred body after CPM was to cover it up with clothing post CPM. They described their efforts to conceal their scars, lack of breast cleavage and catheter lines. They often wore baggy shirts when out in public. They felt uncomfortable wearing what they described as feminine clothing. For them, feminine clothing included any garments that were tight, frilly or low cut on the chest. They felt that feminine clothing did not suit their bodies without breasts. They shared that they did not have the breast tissue to fill the breast areas of the garments. As illustrated in the following quote from Deanna, 47-years-old, hiding their body was one

way the women could avoid talking about their breast cancer. She described her experience below:

> …I don't know, I just don't like…it's not that I care if people know, I really don't care, but I just find then people start asking questions and they ask questions that I really don't feel that need to ask if they see my scars, because sometimes you can see the scars that I have from my port and they will say oh why do you have a scar there? Well who asks those questions?

For Deanna, intrusive questions such as the one she describes felt disrespectful and offensive to her, as her breast cancer experience is deeply personal, and not needing to be shared with others.

Some women in this study were concerned about their clothing even when they wore breast prostheses because they felt these prostheses looked abnormal. They described the prostheses as being firm and heavy. They explained that the breast prostheses needed adjustment throughout the day to maintain the illusion of breasts. Some discussed feeling restricted in their clothing options. They did not want to wear clothing that would bring attention to their breasts or catheter lines because these were symbols of their cancer experience that they wanted to hide.

Furthermore, some women described heightened discomfort around girl talk about breasts. They found it particularly difficult to hear their friends' talk about breast imperfections because it made the women reflect on the appearance of their own chest. Catrina, 44 years old shared her experience below:

> But one thing I hate is when people talk about their breasts and people talk about their breasts a lot, and you don't realize, until you don't have any…and it is a bit of a piss off. And people don't do it intentionally. People just don't think, right? SO that is something that kind of bugs me a bit (teary), umm…but in the moment, I don't get upset…it is just hard to talk about.

Although Catrina acknowledges that women talking about their breasts during girl talk is unintentional in her presence, it is hurtful and provoked feelings of discomfort and embarrassment about her physical body within her social environment.

Removal of the women's breasts eradicated the ability to breastfeed their present and future children. For some women, this was perceived as a loss in motherhood and was difficult to cope with. They enjoyed breastfeeding and were disappointed when they had to stop breastfeeding as result of their cancer treatment. Alexandra, 34-years old shares her experience of breastfeeding and feelings about having to stop in the following quote:

> That was rough because it was my plan to breast feed, like I said my plan, because if you can stick to a plan when you have a new born, was to hopefully breast feed until he was six months… I wish I had the chance to wean him and enjoy it; I didn't get the weaning process, I didn't get to hold him like that and have that moment with him one more time, which was hard because I really wanted to...I wanted to be able to breast feed a few more times, like I wasn't ready to let that go…

For Alexandra, the early cessation of breastfeeding altered her perception of being whole in the context of a mother's body and being able to nourish her son. Although she described adapting to the loss of her breasts by holding her son to her bare chests to feel that bond between them after CPM, she acknowledged that it did not feel quite the same.

Contributing to the essence of lived body, most women reported that the physical changes to their chests following CPM served as daily reminders of what they have gone through during their breast cancer experience. They described the constant reminder of having had breast cancer each day with simple tasks such as showering, getting dressed and putting on their breast prostheses. Some women described being reminded of their breast cancer experience any time their chests were touched, or when undressing or during times of intimacy with partners. As Deanna, 47-years-old said: "It's not like I'm ever going to forget that I had breast cancer, every day I get dressed I know!"

For some, their chests without breasts provided them with comfort because it reminded them that by having CPM they did everything they could to ensure that breast cancer would not return. They felt empowered by the choice to undergo CPM as it provided them with the sense of longevity of life. They choose this treatment option because they perceived it would provide them with the best probability of life, and quality time with their families and loved ones. This provided them with a sense of comfort and happiness, and they shifted their focus from their battling their disease to making the most of their future.

Having the visual reminder of breast cancer in the form of their mastectomy scars, served as a reminder to slow down, enjoy life, and focus their energy on the things that mattered most, such as spending quality time with their families and loved ones. In this regard, most of the women described the experience of breast cancer as positive, as it forced them to reflect on their values, goals and aspirations, quality of interpersonal relationships with loved ones. They found strength and resilience throughout their breast cancer experience; the physical changes in their bodies did not define them as young women. As Catrina, 44, describes:

> …I don't think my breasts define me. When I think about how to describe myself, and some of the positives that happened because of breast cancer, I think of myself as a mother, wife, and health care provider. I think I am a stronger person because of this, and I try to model that for my kids…

Although she has had her breast removed, Catrina describes how her breasts did not define her as a wife, mother, employee, or friend. She has become stronger because of her breast cancer experience.

Furthermore, the small challenges and quarrels they encountered within their daily lives with family and friends seemed less important after battling breast cancer. As Elena, 33 describes….

> a positive is just the way we look at life now, we don't have the negativity that we had before; we don't fight over spilled milk any more or argue over the stupidest

> little things…I don't think we have argued this past year or whatever; it is just that little things don't matter anymore, it's just the big picture.

Elena describes how her relationship with her husband has changed after her breast cancer experience. Both herself, and her husband now choose to focus their energy on things that truly matter in life, not allowing themselves to become worked up over petty arguments regarding material things.

The women in this study described their needs for support in learning how to find opportunity in their breast cancer experiences, focus on new goals, and learn to appreciate life. The experience of breast cancer gave most women a different perspective on life, as Becky, 30-years old describes:

> …I've gotten some more perspective on what actually matters to me in life, like I've got this job that I don't like and I feel like I'm wasting my time at so like maybe I should do something about this. So cancer has really given me this sense of urgency to do something that matters to me instead of just going through the motions.

For Becky, her breast cancer experience enhanced her appreciation for life. Her appreciation for life's uncertainties empowered her to seek out meaningful opportunities, as she describes in the context of her employment in the example above.

Learning to accept their new bodies following breast cancer and CPM has been a challenge for these women. Improving their sense of self as "normal" women during the cancer experience and survivorship required support from relationships with partners and

health care providers. As they experienced survivorship, the women developed a sense of femininity despite the absence of their breasts.

Themes

In this section, a detailed description of the three themes that emerged from the interviews is presented: 1) My breast decision: Empower me to make informed treatment decisions about my breast health; 2) Defining a new normal for intimacy post CPM; and 3) Supporting me in coping with my chest without breasts.

My breast decision: Empower me to make informed treatment decisions about my breast health

This first theme describes the women's perceptions of personal CBC risk and the decision to undergo CPM in efforts to reduce that risk. CPM alleviated some concerns related to future CBC risk, however, most women did not describe peace of mind post CPM. This theme developed from the women's need for clinical support in making informed decisions about their CBC risk, including the risks and benefits of undergoing CPM.

The diagnosis of breast cancer was shocking to all the young women; it was a reality that hit them like a ton of bricks. Some felt the diagnosis in and of itself was absurd. They were young women in the prime of their lives; seeking career opportunities, dating men, planning for children, and raising families. Breast cancer was not in their life plans; it was not something they anticipated would happen to them. For the two women

who had a family history of breast cancer, they did not anticipate breast cancer happening at a young age. For example, Becky, 30-years-old, said:

> Everything felt absurd, just completely ridiculous; it seemed impossible. I laughed at the doctor, told him that he wasn't saying everything that he was supposed to say, he was supposed to tell me that it was fibroadenoma and like I explained all of this to him, I was like no this is what you are supposed to say, you are not supposed to be telling me I have cancer.

In this quote, Becky is describing her personal reaction to her breast cancer diagnosis. The shock that accompanies this reaction was common to all women in this study.

All women in this study chose to undergo CPM for similar reasons. They perceived that it was the best therapeutic option for decreasing the probability of developing future CBC. Preserving life and assuring longevity was at the forefront of the women's minds when first diagnosed with breast cancer. They took comfort in exhausting every therapeutic option available to mitigate their risk of developing future CBC. The women choose CPM because they could not bear to deal with another diagnosis of breast cancer in the future. They did not feel they would be able to cope with breast cancer later in life. Most believed they would cope poorly if they were diagnosed with breast cancer again. They thought the outcomes of cancer treatment would be poorer if they had breast cancer at an older age – that is, they would be more likely to die and have more complications. They could not imagine attending the frequent appointments that are disruptive to their family lives, if breast cancer was to happen to them again. This

strengthened their resolve to have CPM as part of their treatment for their current breast cancer. Therefore, undergoing CPM was described by the women as an easy decision to make, as it was a way for them to take control over their health. Alexandra, 34-years old described her experience below:

> I knew I would drive myself crazy feeling my other breast every day, 15 million times a day poking and prodding at my left breast and I said I just can't deal with the emotion of it all, driving myself crazy that long and it may never come in that breast, who knows, but I wasn't willing to take that chance. I knew, I knew I would drive myself crazy and also I didn't want to do it in a year's time, two years' time, five years' time to feel a lump and to have to do chemo and a mastectomy and who knows what else or heaven forbid they can't do anything for me at that point so I just said take the left too please.

This quote describes Alexandra's anxiety related to her breast cancer diagnosis, and her reasons for choosing CPM as a treatment option. She chose CPM as it would alleviate her anxiety related to developing CBC in the future. Being a young woman with her life ahead of her, she did not want to spend each day worrying about CBC.

Although most women in this study were convinced that undergoing CPM would reduce future CBC risk, few women were counseled regarding their personal CBC risk and the benefits of undergoing CPM. The choice to undergo CPM was often described as a personal decision. In a few instances, the decision to undergo CPM was discouraged by health care providers for reasons such as risks associated with undergoing unnecessary

surgical interventions, and efforts to preserve wholeness to women's bodies. Health care providers were supportive of CPM if it alleviated anxiety and reduced stress. As Becky, 30-years-old, said:

> I was really worried that I was going to pick to have the bilateral mastectomy and he (surgeon) would be like no that's extreme why are you doing that. But in the end, he just said what have you decided? And, I said bilateral mastectomy. And he was like okay, that's a personal decision, if that's what you want sure. So it was good in the end, but I kind of wanted guidance from him and he wasn't offering it.

Becky acknowledges that although she was satisfied with her choice to undergo CPM, clinical guidance related to personal CBC risk, and the risks and benefits to undergoing CPM were not discussed by health care providers, something she felt would have been useful in reducing anxiety related to making the right choice for her health.

Some women received mixed support from healthcare providers in deciding to have CPM. Some healthcare providers supported women in making this decision, but only if it alleviated anxiety and reduced psychological morbidity. Deanna, 47-years-old, explained that her physician agreed to perform the surgery:

> Well there is concerns having surgery, you know you are being put to sleep and you could have infection and all of that sort of thing. And, I came back with him and said I have three children. I have to live for them. And, I would rather die trying

than live with something in the back of my mind all of the time thinking that it is there; I will drive myself crazy. So obviously he relented.

In Deanna's experience, her healthcare provider was accepting of her choice to undergo CPM as it was anticipated to reduce her anxiety and fear of CBC recurrence.

Some women were advised by healthcare providers to not have CPM because of the risks related to general anesthetics and surgical complications. Others were simply told by healthcare providers that CPM was an unnecessary surgical procedure and because it was unnecessary, there was no further discussion about it. Still others were not given any reason as to why CPM was not recommended for them. For those women who were married, their partners supported them in making treatment choices that they felt necessary for their health. They were not concerned about the loss of their wife's breasts; ensuring life and longevity for their wife's was at the forefront of their minds.

Most women in this study had CPM without knowing their genetic profile for breast cancer risk. Their decision was not informed by the results of genetic testing. The women explained that having these results would have helped them understand their CBC and make a more informed decision. This was especially important when the women did not have a family history of breast cancer and were relying on the results of genetic testing to help them decide. Elena, 33-years old describes her experience of genetic testing and its importance related to making decisions about treatment:

…to me having the triple negative…I have the gene is the way I looked at it. And then when I had the gene testing done and it came inconclusive, so to me it wasn't

> worth the risk of waiting another couple of years to get retested or whatever like it could come back in that time. So yeah, I just wanted them gone…it is always in the back of your head. Am I making the right decision; it is always well what if I really don't have the gene and I'm just doing this for nothing, but then the more I looked at it and the more me and my husband talked about it, my mom, it was just…that was the right thing to do …it was an easy decision I guess when it came down to it.

For Elena, undergoing CPM was empowering. She felt she did everything in her power to reduce CBC risk, without having knowledge of her family history and genetic testing.

The women described how the decision to undergo CPM felt for them in lived time. Some felt hurried in their decision to undergo CPM. They felt their breasts could not be removed fast enough as they perceived their risk of developing CBC as high. Others however, felt it only necessary to remove the cancerous breast immediately, and required some time to cope before having the healthy breast removed by CPM, choosing to have it removed several months later. The women's husbands, partners, friends and family members supported their decisions to undergo CPM both immediately and months after the initial mastectomy. They trusted that the women were making informed treatment choices necessary to promote their health. This sense of urgency is illustrated in the following quote from Alexandra, 34-years-old:

> …hurried in a sense, not by the medical professionals, but hurried by the thought that I want these off my body, like I need them gone for the peace of mind. You know you see those t-shirts that said "my real ones tried to kill me"; it was I feel

like a lot of women go through that, like I just want them off, it is a part of me that is actually attacking my body, I need them gone.

This quote illustrates the necessity of having both breasts removed as fast as possible upon receiving her diagnosis, as she perceived her breast cancer as an imminent threat to her livelihood.

Most women took comfort in the fact that cancer could no longer return in their breasts because they had none. Despite this, some women acknowledged the possibility of recurrent cancer, or metastasis within other tissues and organs. They acknowledged that undergoing CPM did not eliminate the risk of cancer in the future. This thought remained at the back of their minds, leading them to adopt the attitude that life is precious, and never to take a moment for granted.

Defining a new normal for intimacy post CPM

The theme of defining a new normal describes the women's experiences of sexuality post CPM. For the women in this study, intimacy refers to both sexual intimacy and emotional intimacy. It is experienced by the women within their intimate relationships. For many, the ways in which they were sexually intimate with their partners changed post CMP because of the way their body looked and felt. Emotional intimacy (or connection) between the women and their partner generally became stronger and their relationship became more satisfying after CPM. Elena, 33-years old describes how everyday life quarrels seemed less important after breast cancer:

> Other than that a positive is just the way we look at life now, we don't have the negativity that we had before; we don't fight over spilled milk any more or argue over the stupidest little things like…I mean I don't even know…I don't think we have argued this past year or whatever; it is just that little things don't matter anymore, it's just the big picture…

Emotional intimacy was important for the women in this study. They perceived their sexuality as encompassing more than physical intimacy. Having undergone CPM reduced anxiety and fear related to CBC risk, shifting their focus towards enhancing and strengthening their emotional intimacy with their partners through improved communication and emotional connection.

When first confronted with the diagnosis of breast cancer, the women described wanting to have the tumors removed as fast as possible. They did not think about how breast cancer and its treatment may impact their sexuality, intimacy with partners, or quality of life in the future. Some were not emotionally or psychologically prepared to accept the changes to their bodies after CPM. Despite having conducted personal research of mastectomy scars prior to undergoing CPM, many women did not expect the cosmetic changes of CPM as having such a large effect on their lives. Some described their sorrow and discomfort with viewing their chests following CPM. Others described the need to stare at their chests in the mirror, attempting to process and accept the body they saw in the mirror. Alexandra, 34-years-old, described grieving the loss of their breasts:

> …when the nurse came in to change my dressing and I looked down at my chest it was horrifying, just horrifying. They had put, I call them the Frankenstein staples, they were just all the way across my chest and it was hard to look at a body that I was looking at for 33 years, like I'm not going to lie…The nurse took off the bandages and I sobbed for quite some time but it was a decision that had to be done, but you definitely grieve; you grieve what you looked like before and you realize how lucky you actually had it before.

Although the experiences of viewing their chests post CPM were unique among the seven women in this study, the feeling of shock and disbelief was common among them.

When participants described their sexuality in the context of their intimate relationships with their partners, insecurities about their new body emerged. They felt they needed to conceal their chests when being sexually intimate with their partner. The way in which they experienced lived space during intimacy changed. They did not feel comfortable exposing their bare chest to their partners, or engaging in skin to skin contact with them. They needed physical space between their chests and the chest of their partners, as they felt their chests were no longer feminine. They felt insecure exposing their bare chests without breasts during intimacy, despite having reassurance from their partners that they were in fact beautiful and attractive even without breasts. Some women were intentional in wearing clothing like big, bulky t-shirts to conceal their scarred chest when they were sexually intimate. They no longer felt comfortable wearing sexy clothing like lingerie. The following quote illustrates how some of the women struggled with

changes in their lived bodies and self-identity post CPM. As Catrina, 44-years old describes:

> …we never have sex without me having a shirt on… I don't know if it is a reminder, or to me, like…I wonder…I don't want my husband to feel like he is chest to chest with one of his hockey buddies or something, you know what I mean?... Like, I don't know that side of it and I don't…and I don't want to ask…and I don't think he wants to ask…maybe someday we will, but not yet.

The women described changes in emotional intimacy within their relationships post CPM. Some women expressed feelings of insecurity related to losing their breasts and how that may impact their lived relationships with their partners. Participants shared that their partners were supportive during the decision-making process to undergo CPM, and after the procedure was performed. They were told by their partners that their breasts did not define them as women, and that having them alive and well was of the upmost importance to partners. The following quote illustrates how the women's insecurities within their lived relationships with partners post CPM. As Elena, 33 years old describes:

> I think it was more hard for me to make the decision based on how he would feel about me, not necessarily how I would feel about me…. Because everything goes through your head, you're like is he going to love me; is he going to want to look at me, you know what I mean.

The above quotes are examples of how perceptions of femininity and desirability were affected by CPM, and the discomfort women experienced with revealing their bare chests

to their partners during sexual intimacy. They were concerned about their partners' reactions to their chests, despite reassurance and support from them that they were beautiful and attractive

For the women in this study, emotional intimacy with their partner was described as a closeness that allowed them to share their feelings and show how they cared for each other. It became stronger after CPM for many of the women who were in an intimate relationship. They felt supported in their decisions to undergo CPM. Their partners encouraged them to choose CPM because it was the treatment option that would help them live longer. Their partners were not concerned about the mastectomy scars that would be left after their breasts were removed, because they wanted their wives to be present so they could share their lives together. Partner support strengthened the women's intimate relationships. They described feeling a stronger connection to their partners due to enhanced communication and partnership, as Deanna, 47 years-old describes:

> …like I think my husband and I really joined together after that because we had this battle to fight and again we were busy…the breast cancer was only a small part of the day because these kids need to be looked after. My oldest was in school so there was homework every day, you know printing and writing and all of that stuff so it just seemed that breast cancer was just something that we lived through and it brought us closer together, there was no question that it would.

This quote illustrates that day to day life must go in within family households despite chronic diseases such as breast cancer. The women worked together with their husbands

in efforts to minimize disruptions to their family life while enduring breast cancer treatment. This partnership resulted in enhanced communication among the couples as they shifted their energy towards enjoying quality time with their loved ones.

Supporting me in coping with my chest without breasts

The final theme captures the thoughts, feelings, and experiences of the women as they attempt to cope with their new bodies post CPM, and highlights their support needs for recovering from breast cancer and its treatment. All women needed information on how CPM would affect their sexuality, and emotional and sexual intimacy. More explicit information was needed for anticipation of physical bodily changes post CPM. They described their need for counselling, both individually and couples' therapy as lived relationships had changed post CPM. They also described the need for support as they learned to accept their new selves after CPM and breast cancer. As Elena, 33-years-old, explained:

> I think it is the way I look at myself, or view myself…. I'm working on it with my therapist, but I have extremely high standards and the standards… …it's just how I feel about myself and sometimes not feeling like a woman and stuff like that I guess is kind of the hardest thing for me, but I guess accepting the new me is what I'm currently working on.

This quote illustrates how some of the women developed an altered sense of self related to not having the "normal" body image expected of women in Western society. However,

they recognize that their disease does not define them, and they work to embrace and accept a new sense of self post CPM.

Most important for the women in this study was the need for counselling and education prior to undergoing CPM to better prepare them for alterations to body image following CPM and accepting their new bodies. For most, this was not offered. Furthermore, the women disclosed that they were not emotionally or psychologically prepared to view the cosmetic results from the mastectomies. Little to no support was provided in terms of what the women could expect from mastectomy surgery cosmetically. The following quote speaks to one woman's reaction to the changes in her lived body post CPM, highlighting the need for support in preparation for viewing one's chest without breasts. As Giselle, 42-years-old explained:

> I was in my bed. I asked my daughter to go get the mirror, and it wasn't as bad as I thought, but when I saw those staples I screamed because all those staples will leave a lot of marks, so yeah…I was not prepared to see that they removed all the muscles, the pectoral muscles were gone. It was the skin and the bones.

Viewing their chests post CPM for the first time was difficult, it was something the women did not feel prepared for, even after researching mastectomy scarring prior to undergoing surgery.

A few women raised concerns about how breast cancer would affect their sexuality regarding preserving womanhood in the context of breastfeeding, and their ability to bear children in the future following breast cancer treatments. They reported that healthcare

providers discussed with them the possibility of infertility following chemotherapy and recommended cessation of breastfeeding. There were no discussions about sexuality initiated by health care providers and the women did not feel comfortable initiating this conversation. They did not consider how CPM and other cancer treatments would impact their sexuality and intimacy with their partners.

As they transitioned into survivorship, participants were faced with concerns related to their return to work and career goals, sexuality, fertility, emotional distress, physical complaints, and social relationships. They did not anticipate these problems. The women reported having little support for the transition to survivorship following breast cancer. When they sought support, it was not accessible. Support was often expensive, or not fully covered by insurance plans. For some women, supportive services required them to drive long distances to neighboring cities. Therefore, these women had to take a day off work, drive long distances, pay for parking, and pay for the service, all of which resulted in financial burden and cessation of supportive services. Giselle, 42 years old described her experiences below:

> Yeah, I talked to my surgeon about it because there are some things that can be done, some physiotherapy can be done to rebuild muscle and all that, there are a lot of things that can be done, and my surgeon told me that, well, because of the medications that you take, I can't help you…so I went to see a psychologist…but I had to stop because it is too expensive and nobody reimburses that…it is $120 every time we go and on top of all the parking expenses and the days lost at work

> and the extra fees of everything since the cancer, I just can't afford it…I go to physiotherapy once a week and you know, it has been 5 years at 55 dollars per week, you can count how it goes, so to add the psychologist and psychiatrist I would have to sell my house so…what is covered is not helping, you know seeing a psychiatrist to get a prescription filled, that is not my point. I want to see someone to talk, and they just say, you look depressed so they give you a pill, and then another to counteract the side effects of that pill…I stopped taking everything. I cancelled all my appointments with all my doctors, and at least I do not have that stress to deal with, through all the appointments that have been rescheduled and rescheduled, and they give you appointments at 10 am when you are working, and you have to travel an hour to get there, and an hour back, the whole day has to be taken off…

The quote above describes feelings of disappointment with supportive care services, and highlights some of the common barriers to accessing support. Furthermore, some women described feeling abandoned following completion of their cancer treatments. Other than follow-up visits to their oncologist and family physician a few times a year to monitor physical well-being, there was no support or guidance offered to the women related to their psychosocial, emotional, or sexual wellbeing. In addition, the women also felt their concerns were dismissed by healthcare providers. For example, Giselle, 42-years-old, described her experience with health care providers during her cancer experience as being overly reassuring. Whenever Giselle raised concerns related

to the treatment side effects of CPM (pain to chest wall), fatigue, weight gain, and vaginal dryness, all resulting in diminished sexual pleasure, she was constantly reassured that everything would return to normal following her cancer treatments. However, she did not feel the bodily changes she developed during treatment returned to normal, negatively affecting sexual and emotional intimacy with her husband. She did not feel she was given any education or counselling on how to cope with the changes in her body, or referred to a sexual counsellor. She explains below:

> You know, had I known these things, I feel like they would have helped me in the long run. I would have done it [interventions to maintain intimacy during cancer treatments]…but no one said anything (teary). They [healthcare providers] said, don't worry about it [changes in body, low sex drive]. Everything will come back, you know that magic phrase that everything is going to come back and don't worry about it. They are the professionals; they are the ones who are supposed to know that.

Her experience was not unique, as others described that they felt that support would have been beneficial at some point during their cancer experiences. Some women believed that these interventions would have been most beneficial if introduced very early into cancer treatment planning. Knowing what to expect in terms of changes to their bodies would have help them by developing coping mechanisms to deal with bodily changes before they arose. They felt ill prepared to deal with the changes in their bodies. They were not

counselled about the impact breast cancer treatment might have on their sexuality. One woman disclosed that a small pamphlet had been given to her on sexuality, and she was advised to seek information from the Canadian Cancer Society. She explained that these resources did not sufficiently attend to her concerns. As they entered survivorship, the women believed that couples' therapy would have been beneficial as they attempted to regain normalcy within their intimate relationships with their partners; however, this was generally not offered as Alexandra, 34-years-old shared:

> …anything related to sex at all was chemo may put you into menopause, it may not. Everybody is different. And, we have had women who after chemo have had healthy babies. That was pretty much all that was said. Nothing around you are going to need to be comfortable having sex with your husband before you have a baby. That was never mentioned once all that was said was you might have a child again who knows, but that was all that was said.

All women felt that discussion about changes to their sexuality would have been beneficial. Having health care providers bring up the topic of sexuality would have created a safe space for them to discuss their concerns, however, that was not offered, and the women seldom communicated their concerns feeling as though they were not important.

Some women discussed how recovering from the cancer experience requires more time than recovering from the cancer treatments specifically. For example, Alexandra, 34-

years-old, explained that she believed psychosocial and psychosexual support to be of value during survivorship:

> …there was no follow-up for me in terms of my emotional health, my mental well-being after they fixed the medical, like the science that we can fix you with, umm...but at no point was there even an offering of did you want to see a social worker. We have support groups, if that. There was nothing, which is very sad because it...now being on this side of it. I've heard it so many times that recovering from cancer takes longer than the actual treatment of cancer…There are days that are a lot harder than when I was going through treatment, which is strange, you would never think that.

This quote highlights the women's described needs for ongoing, integrative psychosocial care that addresses concerns in a holistic manner. This was perceived as lacking within their health care experiences in the context of their breast cancer, treatments, and survivorship.

Summary

The essence of these young women with breast cancer's lived experiences of sexuality following CPM is described as "My body is scarred, but for that I am stronger". The three themes that emerged from the essence are, 1) My breast decision: Empower me make informed treatment decisions about my breast health, 2) Defining a new normal for intimacy post CPM, and 3) Supporting me in coping with my chest without breasts.

The women described the lack of sexual education, counselling and support related to sexuality following breast cancer and CPM. As love and intimacy are essential for psychosocial growth and development of young adults, it is essential that health care providers offer support and counselling related to sexuality to young women with breast cancer at all stages of cancer care, including survivorship. Sexuality is an important element of intimate and social lives, and must be addressed by health care providers in a holistic manner.

Chapter 5: Discussion

This chapter discusses how the findings of this research study can be used to advance nursing practice caring for young women with breast cancer post CPM. It brings to light some of the challenges experienced by these young women as they attempted to make sense of their sexuality post CPM. The strengths and limitations of this study are acknowledged. Lastly, recommendations for future research are provided.

Research Findings

This phenomenological study examined the lived experiences of seven young women with breast cancer following CPM. To date, this has been the only qualitative study that has examined the meanings of sexuality specific to young women with breast cancer following CPM. Previous studies have examined the impact of CPM on women's sexuality and quality of life, however, the focus was on women of all ages, not young women specifically (e.g., Frost et al., 2006). In this study, the meanings that each woman attributed to their experiences of sexuality were unique. Yet, there are several themes representative of their experiences that contribute to the essence of this study, which is described as "My body is scarred, but for that I am stronger".

Women's perceptions of their personal CBC risk impacted their decision to `undergo CPM to reduce this risk. The perceptions of risk are described in the theme, "My breast decision: Empower me to make informed treatment decisions about my breast health." In this study, most women made the decision to undergo CPM prior to having the results of their genetic testing. Treatment decisions were made without knowing if they

were truly at risk of developing CBC. It has been documented in the literature that women may overestimate their risks of developing CBC (Agarwal et al., 2015; Anderson et al., 2017; Davis et al., 2015; Lostumbo et al., 2010; Rosenberg et al., 2013; Tesson et al., 2017). Women may benefit from having education and counselling related to the results of their genetic testing and personal risk of developing CBC to make informed treatment decisions that aim to mitigate their risks of developing CBC. This has been documented as an area for concern in the medical system, as health care providers are not providing adequate education and counselling to women regarding personal CBC risk, and the risks/benefits associated with choosing CPM as a treatment option (Bellavelance et al., 2016; Katz et al., 2017). The women in this study perceived that they were at significant risk of developing CBC in the future. Some women were not counselled about their actual breast cancer risk, or the risks and benefits they could anticipate from undergoing CPM. Many of the women reported that this information and clinical guidance from health care providers in the decision-making process would have been helpful, even though they felt it may not have resulted in a different treatment course. Similar findings have been documented in other research studies on young women's knowledge of CPM and perceived risk related to developing future CBC (Anderson et al., 2017; Baker et al., 2013; Davis et al., 2015; Lostumbo et al., 2010; Rosenberg et al., 2013).

All women in this study chose CPM because they believed this to be the best treatment option for their health. Their decision to undergo CPM alleviated anxiety and

stress, and offered them a sense of peace of mind and longevity. It has been reported that young women with breast cancer experience more emotional distress compared to older women for a variety of reasons which include increased difficulty facing mortality at a young age, fear and anxiety related to how families will cope with their diagnosis and illness trajectory, body image disturbances, early menopause, and infertility, and less established coping mechanisms and social relationships (Adams et al., 2011; Campbell-Enns & Woodgate, 2015; Diaconu et al., 2015; Rees et al., 2017). Younger women experience more anxiety and stress related to the fear of recurrence compared to older women (Campbell-Enns & Woodgate, 2015; Rees et al., 2017). For them, with so much of their lives ahead of them, CPM offered the best assurance of longevity. They were satisfied with their choice to undergo CPM. High satisfaction rates with CPM have been reported in other studies, suggesting that undergoing CPM does not negatively influence quality of life (Anderson et al., 2017). Decreased risk of metastasis has been identified as another major factor contributing to women's decisions to undergo CPM in the literature (Rosenberg et al., 2013).

For women with breast cancer, education and counselling related to the benefits versus risks related to undergoing CPM is not routinely included in cancer care (Lostumbo et al., 2010; King et al., 2011). In this study, the women reported varying levels of support from health care providers in understanding their personal risk of developing CBC and benefit CPM serves in reducing risk of future CBC. Only one woman in this study felt she was counselled properly to undergo CPM because of her

strong history of familial breast and ovarian cancer and presence of the BRCA II mutation. Half of the women in this study were educated to some extent about the risks versus benefits of undergoing CPM. Reasons given by health care providers to refrain from CPM included preserving wholeness to women's bodies, and risks associated with undergoing unnecessary surgery (e.g., removing health tissue, risk of infection, and the risks associated with anesthetics). Even though some women were advised that they did not need to have CPM, they felt they were not adequately counselled regarding their personal risk of developing CBC, and therefore, still chose to undergo CPM as a mechanism to prevent CBC in the future. The findings regarding education and counselling about CBC risks and disclosure of clinical benefit to undergo CPM are consistent with what has been documented in the literature (Lostumbo et al., 2010; Brewster & Parker, 2011; Rosenberg et al., 2013). In Rosenberg et al. (2013), 51% of young women with unilateral breast cancer disclosed receiving clinical reasons for not undergoing CPM. In addition, BRCA mutation carriers had a more accurate assessment of personal risk of CBC, while non BRCA mutation carriers overestimated actual CBC risk; a finding consistent with what women reported in the present study as two out of the seven women possessed BRCA mutations and had a maternal familial history of breast cancer.

Undergoing CPM negatively impacted the women's sexuality and quality of life during each stage of their cancer experiences, with the most profound effects described during survivorship; captured in the theme, "Defining a new normal for intimacy post

CPM". Consistent with previous studies (Anderson et al., 2017; Frost et al., 2006), most women in this study reported that undergoing CPM resulted in diminished body image, which contributed to diminished sexual intimacy through altered feelings of femininity and attractiveness. Furthermore, Rosenberg et al. (2013) documented that young women with breast cancer described feeling worse about their appearance than expected following CPM, and 42% reported their sense of sexuality was worse than expected. Another study conducted by Anderson et al. (2017) identified that women who underwent CPM without breast reconstruction reported the most unfavorable perceptions of body image.

Most women in this study grieved for their bodies as they once were, and desired to feel like "normal" women in the context of the intimate and social domains of their lives. This concept of attaining a "normal" appearance for a woman is largely influenced by societal expectations for women's bodies. A research study conducted by Ruben and Tanenbaum (2011), identified that women felt pressured by society and the health care providers to undergo breast reconstruction following surgical treatment for breast cancer in efforts to avoid stigmatisms associated with having a chronic illness, and to achieve a sense of wholeness (Ruben & Tanenbaum, 2011). Interestingly the women in the present study did not share this experience regarding contemplation of breast reconstruction.

Most young women in this study described having an altered sense of femininity and attractiveness related to undergoing CPM, findings that have been reported in other studies (Anderson et al., 2017; Rosenburg et al., 2016). The changes in women's bodies

altered their sense of sexuality in the context of how they experienced intimacy with their partners. Developing acceptance for their new bodies as young women experiencing survivorship following breast cancer was challenging, a work in progress, and an important component of trying to achieve a new normal for intimacy post CPM.

Findings indicate that young women with breast cancer following CPM feel abandoned by health care providers. This is reflected in the theme "Supporting me in coping with my chest without breasts." The need for continued care and counselling related to reintegration into normal everyday life following cancer in young adults is well documented in the literature (Adams et al., 2011; De et al., 2011; Katz, 2014). Young adults with cancer possess unique psychosocial needs related to forming and maintaining meaningful social and intimate relationships, as well as achieving career goal concerns and securing employment (Adams et al., 2011; De et al., 2011; Diaconu et al., 2015; Katz, 2014). Most women in this study identified the need for psychosocial support provided by health care providers as they entered survivorship to facilitate the transition into their normal lives as young women. Although few women sought support from other women in coping with breast cancer, CPM, and changes to sexuality, all women believed that sexual counselling, education, and support from health care providers may have positively impacted their sexual well-being and overall sense of self. Despite this, health care providers were reluctant to discuss women's concerns related to sexuality, except in instances of reproductive challenges and menopause, findings that have been supported in other studies (Katz, 2011; Katz 2012; Kedde et al., 2013a &b). No psychosocial support

was offered to women regarding sexuality or return to life as a young adult after cancer. Some women were referred to the Canadian Cancer Society for information, or given a pamphlet related to sexuality. However, the women expressed the need to verbally communicate sexual concerns with health care providers, psychologists or sexual counsellors. In one instance, a woman attempted to seek care from a psychologist to discuss her challenges with sexuality and intimacy within her relationship with her partner. Unfortunately, this service was not available at the local cancer treatment center. It was not accessible to her because she did not have insurance to pay for this service and to cover expenses associated with it (e.g., absence from work and fuel). Another woman sought counselling after CPM to enhance self-acceptance and confidence with her new body, and within relationships.

To date, research examining the effects of CPM on women's sexuality have been mostly quantitative in nature, in which women were asked to rate their perceptions of femininity, attractiveness, and sexuality using one to two word descriptors, rather than describe their experiences narratively (Anderson et al., 2017; Rosenberg et al., 2013). To better understand the psychosocial needs of young women with breast cancer, a focus on qualitative methods is needed to delve deeply into the meaning of their experiences to provide patient focused, quality care. Most studies identified in the literature review did not explicitly define the term femininity, limiting that quality of the research findings examining this aspect of women's experiences post CPM. Furthermore, understanding young women's experiences of sexuality post CPM would be significantly enhanced

through understanding spousal perceptions and reactions to CPM; to date, this has not been explored. Lastly, much of the medical literature defines CPM as being an appropriate treatment choice for women who possess BRCA mutations and/or a family history. Future research should examine the unique risk of developing CBC in young women specifically when evaluating the clinical benefit to CPM, as young women are at increased risk of developing CBC and more aggressive types of breast cancer.

Health care providers must consider the juxtapositions of medicine, social sciences, psychology, and nursing when examining young women's choices for choosing CPM as their preferred treatment choice. In most cases, CPM is not recommended as a surgical treatment option to prevent CBC in women who lack BRCA mutations and a family history (Anderson et al., 2017; Bellavelance et al., 2016; Lostumbo et al., 2010). Although the medical literature acknowledges psychological benefits to women who choose to undergo CPM, it lacks a deep understanding of the unique psychosocial challenges young women face when experiencing breast cancer. To ensure holistic, quality care is directed to young women with breast cancer, a clinical approach must be adopted that considers the perspectives of the social sciences, psychology, and nursing.

Study Limitations

This study has several limitations. First, for some women, CPM had occurred several years ago, and they had some difficulty with recall of details related to stages of breast cancer, and the length of time of some chemotherapy and radiation therapy treatments. However, this lapse in details does not significantly alter the findings of the

study as it does not influence how the women experienced sexuality post CPM. Furthermore, a sample size of six to eight women was sought for the purposes of this research study. Although data saturation was achieved through recruitment of seven women in which no new data emerged, further recruitment of additional women may have given rise to new themes, and therefore an essence different from the one uncovered in this study. This study was open to young women living within Canada; however, the sample was representative of only four Canadian provinces (Quebec, New Brunswick, Newfoundland, and British Columbia) and four were from New Brunswick. Therefore, some aspects related to young women's lived experiences may not be representative of those living in other provinces. It is important to note that no differences existed among the women within the different Canadian provinces in regards to accessing timely and appropriate psychosocial support and counselling. A larger sample size may elicit a richer description of young women's experiences of sexuality after CPM.

The study design was retrospective in that data was collected from young women's memories of the CPM experience. In phenomenological research, lived experiences gain significance "as we (reflectively) gather them by giving memory to them" (van Manen, 1990, p. 37). The lived experience is that which presents to young women as what is true or real in their life and it is through their memories that they assign meaning to their experiences. Thus, this study considers young women's life experiences and consequent meanings and behaviors derived from these experiences to understand what it means to undergo CPM. Lastly, if the women required support following the

interview process, they were referred to their Oncologist or primary health care provider. Although this was not required, in retrospect, it would have been more appropriate to refer to a counsellor with specialty in psychosocial Oncology.

Study Strengths

To date, this is the only qualitative research study identified that specifically examines the experiences of sexuality post CPM in young women with breast cancer. Using van Manen's (1990) phenomenology to examine experiences of sexuality provides an in-depth description of how this experience is conceptualized by these young women. This approach allows the researcher to develop an interpretation of the meanings gleaned from the lived experiences that can be transferrable to other clinical contexts involving young women with breast cancer. Enhanced understanding of how CPM impacts young women's body image, sexuality and intimate relationships may lead to the development and implementation of interventions better suited to attend to their individual needs.

Member checking is an important component of phenomenological research to ensure methodological rigor of the study and validity of the findings (Melynk & Fineholt, 2011). As data analysis occurred simultaneously with data collection, member checking was completed both during the interviews and following, as emerging themes developed from the interviews. Member checking was accurately completed with five women, confirming emerging themes as they developed. Peer debriefing was used as a method to ensure credibility of the study findings. This process occurred through discussions I had with my supervisor to ensure emerging themes that contributed to the essence were truly

representative of the seven young women's lived experiences. Both dependability and confirmability of the study results were achieved through record keeping and audit trails.

In this study, the sample consisted of women who were Caucasian and who completed post-secondary education. This sample is comparable to populations for which there is an increased prevalence of CPM - young women with unilateral breast cancer who are educated and of higher socioeconomic status (Rosenberg et al., 2013). No data exists regarding the experiences of sexuality post CPM for women of varying ethnic backgrounds or those within minority groups. Although commonalities in women's lived experiences existed, it is important to note that the study findings are not transferrable to other settings, and cannot be generalized as in quantitative studies. There were no expectations in this study that the findings would be generalizable to all young women who had CPM or that the study could be replicated to yield the same data. It was anticipated, however, that the study would foster an understanding of young women's experiences, sufficient to inform for future research.

Implications for Nursing Practice

Many of the women in this study described feeling abandoned following completion of their cancer treatments. Their follow-up care focused on physical well-being rather than the more complex and less often acknowledged psychosocial well-being. There was no support offered to the young women in this study related to their psychosocial, emotional, or sexual well-being, which represents a gap in care that nurses could fill. Nurses can provide support to young women with breast cancer as they

transition into survivorship by assessing and responding to the women's psychosocial and psychosexual needs, and advocating on their behalf for access to timely and appropriate services. Furthermore, nurses can offer education and counselling through a holistic lens to young women with breast cancer. A holistic focus is crucial in assuring attention to psychosocial needs and concerns that may be experienced within every stage of the cancer trajectory, including survivorship. Young women need support to return to their lives as young adults after cancer, especially in the context of intimate relationships. Young women want to feel like "normal" women. Nurses should refer young women to resources available in their community, such as the Canadian Cancer Society, and local breast cancer support groups in the area.

Young women need to be aware that all cancer treatments including chemotherapy, radiation therapy, endocrine therapy and CPM may impact their body image, sexuality and quality of life. Nurses can prepare young women for the changes they will experience in their lived bodies resulting from whichever treatment is chosen. The timing of discussions related young women's concerns about side effects of cancer treatment is an important consideration. When young women are diagnosed with breast cancer, they are focused on treatment options and prognosis (Katz, 2011). Survival and livelihood shifts to the forefront of their minds as they yearn for achievement of important developmental tasks within their life stages of young and middle adulthood (Anderson et al., 2017; Katz, 2011; Rees et al., 2017). Introducing the topic of sexuality early on during the young women's treatment trajectory communicates to the women that

it is safe for them to ask questions and explore areas of concern. Young women need time to engage in these discussions as such, discussions may require dedicated meetings with the nurse outside of cancer treatment visits.

As the trend of CPM is growing among young women with unilateral breast cancer, it is important for nurses to assist young women in understanding their personal risk of developing CBC as well their treatment options, including CPM. Nurses can assess young women's reasons for preferring CPM, and counsel them on the risks and benefits of CPM. Nurses can explain to young women that CPM is recommended for women with the highest risk of CBC - women with a family history of breast cancer or for those with a genetic mutation such as BRAC I and BRCA II. Despite these recommendations, nurses must shift priority to hearing the women's concerns, and support them in making personal choices related to their health that they feel empowered to choose. Nurses examine women's reasons for choosing CPM, and seek to understand those reasons by learning about the women's past experiences with breast cancer. They advocate for women's choices by ensuring their concerns and preferences are heard by interdisciplinary team members. Although CPM is not recommended for all women, it will be important for nurses to support each young woman's decision about having CPM because young women want treatment options that are consistent with their preferences and values. As young women reported in this study, having CPM was the treatment decision women made despite the medical advice suggesting CPM was unnecessary. For these women, having CPM satisfied their need to do everything they could possibly do to

reduce their risk of CBC. It meant they would be around to see their children grow up and it meant they would not need to go through breast cancer treatment again.

Implications for Nursing Education and Research

This study contributes to the existing body of knowledge on young women with breast cancer by helping nurses understand the lived experience of these young women. While recognizing that each young woman's experience is unique, these findings can serve as a starting point for conversations with young women about their experiences, regardless of disease states. Nurses may benefit from learning about how to effectively engage young women in therapeutic conversations about their health situations, as much can be learned about the experiences and supportive care needs through this method. Nursing education should continue to emphasize the importance of holistic care because as the young women in this study emphasized, breast cancer and its treatment impacts all aspects of health. An important, but often neglected aspect of young women's health is sexuality. Nurses need to learn how to incorporate addressing issues of sexuality in psychosocial assessments of young women, in general, and with breast cancer specifically. Incorporating sexual health into nursing curriculum is needed so nurses have opportunities to become competent in addressing young women's concerns about sexuality, body image and healthy intimate relationships.

Findings from this research study support themes previously reported in the literature and highlight young women's voices about their lived world after CPM. Further research is needed that focuses specifically on each of the themes identified in support of

the essence of young women's lived experiences of sexuality post CPM. The study did not reveal any differences in the lived experiences of CPM based on the young women's perceived CBC risk. Because the young women included in this study varied in terms of genetic mutation status, it is not possible to examine how having a genetic mutation or family history of breast cancer impacted young women's lived experiences. Further research is warranted to describe potential differences in young women's experiences with different CBC risk characteristics.

Additionally, this study focused on young women's perceptions. It is important to examine the CPM experience from the perspective of other people who may be impacted by the women's decision to have CPM, such as their partners. In doing so, interventions designed to provide care to couples can be implemented and evaluated. In addition, future research would benefit from examining the experiences of sexuality in young women with breast cancer who opted to undergo unilateral mastectomy, in contrast to those who underwent CPM, to better understand the similarities and differences in psychosocial needs of these two groups. It can be anticipated that young women with breast cancer who undergo unilateral mastectomies may experience more challenges related to their sexuality versus those who underwent CPM. For example, it may be more difficult to find a prosthesis that matches size, shape, and symmetry to the natural breast of the opposite side. This may also be true for unilateral breast reconstruction. In addition, women who have had unilateral mastectomies may feel more insecure exposing their chests with only one breast during times of intimacy in comparison to those who underwent CPM. Lastly,

given the unique psychosocial needs of young adults living with cancer, it is imperative that health care professionals be knowledgeable about the challenges that these individuals face to better provide quality, holistic care that improves quality of life in social, psychological, sexual, and physical domains of their lives. Therefore, further research into the psychosocial needs of this population is essential to enhance current oncology care past the point of treatment and focus on providing quality holistic care.

Understanding young women's past experiences with breast cancer is imperative for health care providers, as it identifies specific elements of the women's emotional distress, and encourages a more holistic and therapeutic approach when caring for these women. Nurses specifically, have an important role in empowering women to make their own decisions about their health (Jerome-D'Emililia et al., 2015; Vaartio-Rajalin et al., 2014). Nurses are well suited to examine women's reasons for choosing CPM due to their holistic focus and ability to advocate for patients in difficult circumstances (Jerome-D'Emililia et al., 2015; Vaartio-Rajalin et al., 2014). They can examine the women's perception of their CBC risk, as well as their past personal experiences with breast cancer and how that has shaped their decisions for treatment (Jerome-D'Emililia et al., 2015). Nurses acknowledge the women's concerns, and communicate those concerns to other interdisciplinary team members to ensure quality care is delivered addressing challenges within physical, psychosocial, spiritual and cultural domains. Furthermore, they reassure the women by speaking positively about her decision, and her right to choose her treatment (Jerome-D'Emililia et al., 2015; Vaartio-Rajalin et al., 2014). Lastly, the nurse

ensures that comprehensive education and counselling is delivered to the women, to empower them to make informed, evidence-based choices that are best suited to their health needs (Jerome-D'Emililia et al., 2015; Vaartio-Rajalin et al., 2014).

Summary

This chapter presented the discussion of the findings. The discussion of the research findings indicated young women from this study had both similar and divergent experiences compared to other research studies. CPM is a growing trend among young women with breast cancer, despite understanding of true survival benefit. The findings of this phenomenological study suggest the need for further investigation into the experiences of sexuality post CPM in young women with breast cancer. They also suggest the need for further assessment of the true survival benefit to undergoing CPM in those who possess a genetic predisposition to developing CBC, and to those who do not. The findings bring to light some of the challenges young women with breast cancer experience post CPM regarding their sexuality. It highlights for the need for more integrated, holistic care that identifies and responds to individual psychosocial needs by providing timely access to supportive services in survivorship. The findings of this study are important, as they highlight the need for health care providers, nurses, and interdisciplinary team members to listen to the concerns, health needs, and treatment preferences of young women with breast cancer when empowering them to make informed decisions about their health. Lastly, strengths and limitations of the study were

presented, and recommendations for nursing practice, education and future research endeavors were suggested.

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Appendix A: Information Letter to Study Participants

Title of research study: Young Women and Breast Cancer: Examining Meanings Post Contralateral Mastectomy

REB #: 2015-036

Researcher and Supervisor: Principal Researcher Megan Williams, Registered Nurse, Graduate Student, Faculty of Nursing, University of New Brunswick, Fredericton, NB, (506) 262-0654 or c6q8q@unb.ca

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Funding: Beatrice Hunter Cancer Research Institute, New Brunswick Health Research Foundation, Atlantic Breast Cancer Foundation, New Brunswick Innovation Foundation, and the University of New Brunswick

Purpose of the study: Some young women who have breast cancer choose to have their healthy breast as well as the breast with cancer removed. This is known as a contralateral mastectomy. I wish to learn about how young women with breast cancer think and feel about their sexuality after having a double mastectomy. What I learn from this study may help healthcare providers better anticipate and respond to the needs of young women with breast cancer.

Study process: Taking part in this study means that you will speak with me about what it was like to have a contralateral mastectomy when you had breast cancer. You will be asked questions about parts of your intimate relationships; such as sexuality. The interview will take about two hours to complete. A follow-up interview will be conducted if you wish to expand on your ideas and thoughts; this second interview is optional.

When we meet to discuss your experiences, it can be at a location that works best for you. If it is not possible to meet in person, we can use an Internet program like Skype. For this, you would need access to a computer with Internet, webcam and microphone. Our conversation will be digitally recorded and typed. The transcripts will be kept confidential and used only for the purposes of this research project.

Confidentiality: Documents that do not require your signature will be assigned a fake name and stored in a locked file. The consent form with your signature will be locked in a separate file away from other forms and written records of your interview. Names and places will be removed from typed record of what you have talked about. This recording

will be permanently removed from the digital recorder after it has been typed. Information will be stored on the study computer for 2 years. It will be protected by a password and only be identified by a fake name. Only the researcher and the graduate student supervisor will have access to your files.

Benefits: There may be no direct benefits to you, although you may find it helpful to talk about your experience of breast cancer and double mastectomy. The knowledge gained from your story may help healthcare providers provide better care to young women with breast cancer who have had a double mastectomy.

Risks: There are no known risks associated with taking part in the study. If you become upset, we will stop talking and we only continue talking, if and when, you feel okay to do so. I will call you within 48 hours of talking with you to see that you are okay. If you wish, we will refer you to local resources such as your family doctor or your oncologist.

Participation and rights: Taking part in this study is your choice. You may withdraw from the study for any reason at any time without consequence. You do not have to answer any questions you do not want to answer. You do not have to share anything you do not want to share. Your participation in this study will not affect your relationship with the University of New Brunswick or the care you receive from health care professionals in Horizon Health Network.

Use of Study Information: Information collected from you will be used for my master's thesis, articles in professional journals and public talks. No real names or places will be used.
Your information may be used in future studies, but only with further ethical approval from research authorities at the University of New Brunswick.

Written records and study summary: If you wish, you will receive a written copy of the record of what you said during your interview. You will also be able to request a summary of the overall study results that may include information from the other women who participated in this study. This summary will not contain any names or identifying information. If you wish, the summary will be sent to you by e-mail or Canada Post.

Additional contact information: This research project has been reviewed by the University of New Brunswick Research Ethics Board. It is on file at REB2014-xxx. This project has also been reviewed by the Horizon Health Network Research Ethics Committee. Should you have any questions or concerns about your rights, you may contact the Research Ethics Office at (506) 453-5189 or ethics@unb.ca.

Appendix B: Informed Consent for Research Study Participants

Research Study Title: Young Women and Breast Cancer: Examining Meanings Post Contralateral Mastectomy

Researcher and Supervisor: Principal Researcher Megan Williams, Registered Nurse, Graduate Student, Faculty of Nursing, University of New Brunswick, Fredericton, NB, (506) 262-0654 or c6q8q@unb.ca

Graduate Student Supervisor: Dr. Krista Wilkins, Assistant Professor, Faculty of Nursing, University of New Brunswick, (506) 447-3077, kwilkins@unb.ca

This research study has been reviewed by the University of New Brunswick Ethics Board is on file as REB: 2015-036. This project has also been reviewed by the Horizon Health Network Research Ethics Committee.

PARTICIPANT QUESTIONS

Has this study been explained to you?	Yes ☐ No ☐
Have you read or had read to you a copy of this consent form?	Yes ☐ No ☐
Have you had an opportunity to ask questions and discuss this study?	Yes ☐ No ☐
Do you understand the information that has been provided?	Yes ☐ No ☐
Do you understand that if you indicate you are at risk of harming yourself or others, your identity will not be protected and you will be referred to an appropriate helping agency such as your family physician or oncologist?	Yes ☐ No ☐
Do you understand that you can withdraw from this study at any time without any consequences?	Yes ☐ No ☐
Do you understand that you will receive a signed copy of this consent?	Yes ☐ No ☐

PARTICIPANT STATEMENT

My signature confirms that I hereby give my informed consent to be a participant in this study.

_____ _____ _____

_____

Printed Name Signature Date

I wish to receive a written record of my interviews. Yes ☐ No ☐

I wish to be notified of any future research project that will be planned based on the findings from this study and to have the opportunity to ask questions about it. Yes ☐ No ☐

I wish to receive a summary of the completed research. Yes ☐ No ☐

I wish to be invited to a presentation of the research findings. Yes ☐ No ☐

Please provide your contact information:

Email: _____

Telephone number: _____

Mailing address: _____

_____

RESEARCHER STATEMENT

I have explained to the above participant the nature, requirements and the purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised. I believe that the participant understands the implications and the voluntary nature of the study.

Printed Name	Signature	Date

Appendix C: Demographic Form

Information gathered in this form will help us get to know you better. All information will be kept confidential.

What is your age? (in years) _____

What is your marital status?

- ☐ Married
- ☐ Common law
- ☐ Single
- ☐ Divorced
- ☐ Other

Do you have any children? If so, how many children do you have? _____
If you do not have children, do you plan to have them in the future? _____

What best describes your area of living?

- ☐ Urban
- ☐ Suburban
- ☐ Rural

Which racial or ethnic background best describes you? _____

What is your highest level of education? _____

What is your current working situation?

- ☐ Full-time
- ☐ Part-time
- ☐ Volunteer
- ☐ Student
- ☐ Other

When were you diagnosed with breast cancer? (year) _____
At what age were you diagnosed with breast cancer? (in years) _____
What type of breast cancer were you diagnosed with?

- ☐ Ductal carcinoma (in situ or invasive)
- ☐ Lobular carcinoma (in situ or invasive)
- ☐ Inflammatory breast cancer
- ☐ Triple negative breast cancer
- ☐ Not sure

What was the stage of breast cancer at diagnosis?

- ☐ Stage 1
- ☐ Stage 2
- ☐ Stage 3
- ☐ Stage 4
- ☐ Not sure

Have you been tested for a breast cancer gene?

- ☐ Yes
- ☐ No

If yes, what were the results of the test?

- ☐ BCRAI
- ☐ BRCAII
- ☐ Not sure
- ☐ Awaiting test results

Who, if anyone, in your family has been diagnosed with breast cancer? (please check all that apply)

- ☐ No one
- ☐ Mother
- ☐ Daughter
- ☐ Sister
- ☐ Aunt
- ☐ Other relative: _____

Please describe your cancer treatments:

	Year Treatment Received	Treatment Site	
Lumpectomy		Left breast	Right breast
Radical Mastectomy (Single or Double)		Left breast	Right breast

Breast Reconstruction (Immediate or Delayed)		Left breast	Right breast
Radiation Therapy		Left breast	Right breast
Other treatments (e.g.,Tamoxifen, Herceptin, chemotherapy, etc)		N/A	

Appendix D: Interview Guide

I would like to ask you about your experience of having a double mastectomy when you had breast cancer and how your sexuality may have been impacted by this surgery. To help you tell your story, I will ask you a series of questions about your experiences.

1. Tell me what life was like for you before you were diagnosed with breast cancer.

2. Tell me about your previous experiences with breast cancer.

    - How did you feel about your family member/friend having breast cancer? Did any family members or friends have breast cancer?

3. Tell me what it was like for you when you were diagnosed with breast cancer.

    - How was your breast cancer discovered? What thoughts came to your mind when you were told you had breast cancer? How did you feel?
    - Which surgical treatment options were presented to you? (i.e., single or double mastectomy)? What did you think about these options? How did you feel about these options?

4. Tell me what it was like to make the decision have a double mastectomy.

    - What led you having a double mastectomy? (i.e., values, beliefs about risk of developing cancer in unaffected breast)
    - What support did you receive in making the decision to have a double mastectomy? And, who provided this support?
    - What were your thoughts when you had the double mastectomy?
    - What were your feelings about having a double mastectomy? Are you happy with your choice in having a double mastectomy?
    - Did you feel hurried in making this decision?
    - When did you have it performed? (i.e., when cancerous breast was removed or some other time after? What led you to having the surgery at this time? (i.e., values, beliefs about cancer risks)
    - Did you consider having reconstructive surgery? Why or why not? (i.e., values, beliefs about cancer risks)

5. Tell me about how having a double mastectomy has impacted how you see yourself (i.e., mother, wife, employee).

    - Tell me about how having a double mastectomy has impacted how you see yourself (i.e., mother, wife, employee).
    - How would you describe yourself before you had the double mastectomy?
    - How has your description of yourself changed?
    - What has been the most difficult part of having a double mastectomy?
    - Tell me about some positive experiences of having a double mastectomy.

6. What changes have occurred in your body as a result of having a double mastectomy? (i.e., losing breasts, pain, scarring, swelling, and infection)?

    - How do you feel about these changes in your body?
    - How have these changes affected your sexuality? (i.e., femininity, attractiveness)
    - Did you expect these changes?

7. How would you experience sexuality?

    - How would you describe yourself as a sexual being?

8. Do you have a spouse/partner?_____
   How has having a double mastectomy affected your relationships with your spouse/partner (i.e., intimacy, sexual function, friendship, emotional connections)?

    - Describe your relationship with your spouse/partner before the double mastectomy.
    - How did your spouse/partner react to your double mastectomy?
    - What has changed in your relationship since you had a double mastectomy?
    - What has stayed the same in your relationship since you had a double mastectomy?

9. Is there anything that I have not covered that you would like to share?

Appendix E: Letter for Recruiters (Horizon Health Network)

My name is Megan Williams. I am a Registered Nurse and graduate student in the Master of Nursing program at the University of New Brunswick. I am conducting research to develop a better understanding of the lived experience of sexuality in young women with breast cancer who have had a contralateral prophylactic mastectomy. I am asking for your assistance in distributing the enclosed information letter to potential study participants. This letter includes information about the research project and an invitation for young women to participate in the study.

For this study, young women aged 20-44 years who have had breast cancer in one breast and who have chosen to have a contralateral prophylactic mastectomy will be invited to participate in a two-hour interview. A follow-up interview will be conducted if participants wish to expand on their ideas and thoughts; this second interview will be optional. I am planning to recruit six to eight young women for this study. There are no anticipated risks related to participation in this study. Study results may help inform health care professionals of the unique psychosocial needs of young women and alert them to assess for psychosexual stress that may negatively impact their quality of life.

I will conduct the interviews in a location and at a time deemed convenient by the young women. The interviews can be conducted either in person or through an internet program, like Skype. All information shared at the interview will be kept confidential. This project has been reviewed by the University of New Brunswick Ethics Board and is on file as REB2015-036. This project has also been reviewed by the Horizon Health Network Research Ethics Committee.

Thank you for your assistance with this project. Should you require any further information regarding the study, please contact me at (506) 262-0654 or c6q8q@unb.ca. Please note that willingness to assist in recruiting is voluntary.

Appendix F: Recruitment Poster

What has it been like to have breast cancer? Have you had your breast with cancer and your healthy breast removed? How has this treatment affected your sexuality? Would you like to help others by participating in a cancer research study talking about your experience?

I am asking young women, aged 20-44 years, who have had breast cancer in one breast and who have had both breasts removed, to talk about how their experiences. I am interested in knowing how this experience has impacted their sexuality. The knowledge gained from this research study will better inform health care providers of the needs of young women with breast cancer and improve delivery of cancer care.

If you require further information or would like to participate, please contact me at c6q8q@unb.ca or (506) 262-0654.

Curriculum Vitae

Megan Elizabeth Huckins

Education

1) University of New Brunswick, Fredericton NB
Master of Nursing, Nurse Practitioner
October 2017

2) University of New Brunswick, Fredericton, NB
Bachelor of Nursing
May 2012

3) University of Lethbridge, AB
Bachelor of Science
May 2010

Scholarships and Funding

Telecote Nurse Practitioner Scholarship, $7500
2016-2017

Canadian Nurses Foundation- New Brunswick Nurses Association Award, $5000
2016-2017

Helen Gibson Memorial Scholarship, $1000
2016-2017

Cutler Nursing Scholarship, $6500
2015-2016

Beatrice Hunter Cancer Research Institute, $17, 850 annually x 2 years
2014-2016 (in association with the Canadian Breast Cancer Foundation- Atlantic node and the New Brunswick Health Research Foundation)- Cancer Research Training Program (CRTP) Traineeship Award

Canadian Institute Health Research, $22,500- (runner up); Alternately Awarded
2014-2015
New Brunswick Innovation Foundation, $9000

Jane Stikeman Ekers Scholarship, $1500
2014-2015

N. Myles Brown Undergraduate Scholarship, $3000
2012-2013

Mr. and Mrs. Conrad J. Osman Scholarship, $1200
2012-2013

Ward Chipmans Founder's Scholarship, $500
2003-2004

Dennis Morris Memorial Scholarship, $1000
2003-2004

Kiwanis Club of Lancaster Scholarship, $500
2003-2004

Conference presentations

1) University of New Brunswick Annual research Day Conference, May 2017
"Breast Cancer in Young Women: Examining Meanings of Sexuality Post CPM"

2) Beatrice Hunter Cancer Research Institute Work in Progress Session, June 2016
"Young Women and Breast Cancer: Defining a "New Normal" for Intimacy post Contralateral Prophylactic Mastectomy

3) University of New Brunswick Annual Nursing Research Day Conference, May 2016
"Defining a "new normal" for intimacy: Meanings of Sexuality in Young Women with Breast Cancer Post Contralateral Prophylactic Mastectomy"

4) University of New Brunswick Thesis Forum for Research Students, March 2016
"Breast Cancer in Young Women: Meanings of Sexuality Post Contralateral Prophylactic Mastectomy-Preliminary Analysis"

5) Beatrice Hunter Cancer Research Institute, November 2014, Research Study Proposal Examining Meanings of Sexuality Post Contralateral Prophylactic Mastectomy Using Qualitative Methods

Professional Membership

Beatrice Hunter Cancer Research Institute
Trainee Member
September 2014-September 2016

Nurses Association of New Brunswick
Registered Nurse
February 2013-Present

New Brunswick Nurses Union
Union member
February 2013-Present