Day Care Surgery and Women’s Breast Cancer Journeys

By

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Introduction

This paper represents a thoughtful and critical examination of the experience of women with breast cancer who undergo day care surgery. In 2009, an estimated 22,700 Canadian women were diagnosed with breast cancer and 9,400 died (Canadian Cancer Society’s Steering Committee, 2009, p.13). Every week in Canada, approximately 437 Canadian women are told they have breast cancer and 100 women die from the disease.

The experience of breast cancer for women has been identified as a complex physical, biological, emotional and psychological “journey” (Halkett & Arbon, 2006). It has been reported that women with breast cancer do not receive adequate health and disease related information at the time of their illness (Jensen, Back-Pettersson, & Segesten, 2000). It has also been noted that women’s needs for support from health care providers are not adequately addressed (Melnyshyn & Wintonic, 2006).

The common thread throughout this project was a focus on women’s emotional and psychological experiences during the phases of the breast cancer journey, from finding a lump, to seeking medical attention, to diagnostic testing and then undergoing day care surgery. Through an in-depth exploration of both existing knowledge and new information related to this important area of nursing clinical practice, this project offers a relevant contribution to the current body of nursing knowledge related to the care of women with breast cancer.

This paper is organized into three major sections related to the care of the women with breast cancer who undergo day care surgery. Part 1 includes the specific
purpose and objectives of the project; the project's background and significance; context and scope; and the author's beliefs about this important clinical practice issue and its clinical relevance to advanced practice nursing. Part 2 is the largest section of this paper. It includes three sub sections which present the findings of the project inquiry. Specifically section 2 includes a comprehensive literature review; my personal observations of women with breast cancer undergoing day care surgery; my reflections and analysis of my observations of the women that had day care surgery; the identification of gaps in nursing knowledge and practice that I noted during my observations and the identification of nursing care needs during the diagnostic and surgical phase of the breast cancer journey. Part 3, the final section of the paper, includes recommendations and conclusions. Specifically this section includes implications for nursing practice, future program planning, questions for future research, potential contributions of advanced practice nurses and project conclusions.

**Part 1: The Experience of Women with Breast Cancer**

This section of the paper includes the following: purpose of the project, specific objectives, the project background and significance, context and scope of the project along with the author's beliefs and assumptions about nursing care for this population of women.

**1.1 Project Purpose and Objectives**

The overall purpose of this project is to carefully explore women’s experiences with day care surgery for breast cancer and identify their needs for nursing care.

Following are the specific objectives of this project:
• To review the literature about women’s experiences with breast cancer in order to inform nursing care.

• To provide advanced practice nursing support for three women who undergo breast cancer surgery (partial or total mastectomies with expanders) at Surrey Memorial Hospital (SMH) and to reflect upon my observations.

• To identify gaps in existing nursing knowledge related to the provision of nursing care for women with breast cancer and their families.

• To identify implications and make recommendations for clinical nursing practice, nursing research and program planning for women with breast cancer including recommendations for the role of an Advanced Practice Nurse (APN).

The next section outlines the scope and context of this project.

1.2 Project Context and Scope

According to the Canadian Cancer Society’s Steering Committee (2009, p. 13 & 14), breast cancer is the most common cancer in women, with more than 22,000 new diagnoses every year. It kills more than 9,000 Canadian women every year, and is exceeded only by lung cancer deaths. One in nine women will be diagnosed with breast cancer, and 1 in 27 will die of breast cancer in their lifetime. Fortunately, largely due to advances in adjuvant therapy, and greater participation in screening programs in Canada and other developed countries, breast cancer mortality rates are now declining. Increasing numbers of women are living with a diagnosis of breast cancer. There are an estimated 162,600 Canadian women alive today (one in every 100 females) who have received a diagnosis of breast cancer in the past 15 years.
In British Columbia (BC), statistics from the British Columbia Cancer Agency: Cancer Type (2009, p.1) indicate that in the year 2007 there were 2,831 new cases of breast cancer diagnosed in females throughout BC and 627 deaths. Fraser Health (FH) is the largest health region in the province encompassing one third of the province’s population. In 2009 in Fraser Health, 969 women were diagnosed with breast cancer and 198 died. The projections in FH for the diagnosis of breast cancer show a steady increase over the next decade: 1001 in 2010; 1,160 in 2015; and 1,330 in 2020. The projections for death from breast cancer within FH follow the same pattern with projections of 201 deaths in 2010; 215 in 2015; and 228 in 2020 (British Columbia Cancer Agency Statistics: Fraser Health Authority, 2009, p. 1).

These statistics are staggering but they do not tell the personal stories behind the numbers. A participant in the Boehmke & Dickerson (2006) study stated, “I’ll never be the same again. I will always be different” (p.1121). This quotation indicates the life changing impact breast cancer had on this woman. I wonder how we as health care providers are meeting the needs of these women during their health care interactions. Are these women truly at the centre of our care processes? Are factors such as education, social status, income, employment and working conditions, social support networks, housing, and living conditions considered when planning care for our patients? Are these factors, ones that strongly influence a woman’s ability to be an active participant in her care, always a part of our assessment and evaluation processes? Is nursing care plans changed based on the results of our patient and family assessments and conversations? In our practices, have we embraced a set of values and beliefs that include respect, human dignity and the belief that patients are the
experts regarding their own lives? Or are we just treating the illness and neglecting many of the woman’s other needs?

Fraser Health (FH) is currently planning a Rapid Diagnosis Breast Health Clinic in Surrey, British Columbia. This new clinic is scheduled to open in 2011 and will offer a continuum of services to provide care to women from suspicion of cancer through diagnosis and surgical treatment. Current practices for women with breast cancer within FH results in a 14-16 week wait for a screening mammography appointment; a 17 week wait for a confirmed breast cancer diagnosis; and a further 6 to 9 week wait for breast surgery. The European Society of Breast Cancer Specialists (EUSOMA) standards of care suggest the optimal timeframe from suspicion of breast cancer to diagnosis should be three weeks and timeframe from diagnosis to surgery be 10 days. The FH timeline for care far exceeds what has become the accepted gold standard of care as set by EUSOMA.

One of the goals of the new Surrey Memorial Rapid Diagnosis Breast Health Clinic (RDBHC) is to decrease the timeframe from suspicion of breast cancer to diagnosis to meet the EUSOMA standards. Completing investigations promptly will reduce the time that women must wait and will help to reduce their overall level of fear and anxiety. The clinic is intended to provide women going through the breast cancer journey with the opportunity to experience patient centred care, improved continuity of care, and the opportunity to receive the necessary information to participate in making informed decisions.
Historically Surrey Memorial Hospital (SMH) has cared for all patients who have surgery for breast cancer as overnight in-patients on the surgical ward. The average length of stay (LOS) for this patient population is 2.2 days (Ko, 2009). This statistic is in stark contrast to women who have day care procedures at other sites (Ko, 2009). If SMH changes current surgical practices for women with breast cancer, i.e., follows the trend to move in-patient breast cancer to the out-patient setting, this change will shorten the time women stay in the hospital setting but will also decrease the contact time with nursing staff who are educated to provide education, psychological support and basic nursing care. The shortened time available for direct nursing care for this population of women is a significant factor in the choice of the nursing issue explored in this project. The third part of Section 1 will describe the background and significance of the issues related to women who have breast cancer and undergo day care surgery.

1.3 Background and Significance

In various cultures, a women’s breast represents (emotionally and symbolically) her womanhood, sexuality, aesthetic appearance, feeding of her infant and feelings of love and motherhood. Women suffer from the idea of losing their breasts and some women experience serious psychological problems and find themselves in a crisis period related to surgery for breast cancer (Langellier & Sullivan, 1998; Demir, Yelda, Ozsaker & Diramali, 2008). Not only is breast cancer the most common cancer in women, breast cancer also threatens an organ that symbolizes femininity and has been extensively studied including the emotional and psychological aspects (Barroso et al., 2000; Love, Lindsey, & Williams, 2005).
Women with breast cancer have been shown to have concerns about body image, sexual dysfunction, anxiety about the illness and treatment, communication problems with their spouses and fear of death (Love et al., 2005; Langellier & Sullivan, 1998; Odling, Norberg, & Danielson, 2002). In addition, it is known that some women experience intense anxiety because of an uncertain future and fear of recurrence of the cancer or metastasis and can become depressed (Ferrell, Grant, Funk, Otis-Green & Garcia, 2001; Fournier & Schafer, 2001).

Women who have a suspicious mammogram or feel a lump or a lesion in their breast may or may not seek medical treatment because they fear that it could be cancer (Carpenter, 1997; Facione, Giancarlo, & Chan, 2000). The thought that they might need a mastectomy as well as realizing that the cancer might not be treatable is sometimes overwhelming to the point that they may ignore their symptoms (Carpenter & Facione et al.). If women seek medical attention and are told that a biopsy is required for a definitive diagnosis, most women want to have the biopsy performed as soon as possible. Unfortunately, long delays for this procedure are very common in our current health care system.

Excisional biopsy is a procedure that is conducted in the day surgery under general anaesthesia. It is documented that the period before, during and after a biopsy is very stressful for patients because of the uncertainty and anxiety they experience (Carpenter; Goodman & Mellon-Reppen, 2001). Although day surgery procedures are reliable and less costly, patients experience the stress of admission, surgery and discharge all in the same day (Otte, 1996). Short hospital stays impact patient-nurse communication, the development of therapeutic relationships with the health care team,
and the ability to provide comprehensive anticipatory guidance and patient education. In
day care surgery settings, nurses have only a few minutes to get to know and
communicate with the patient. This limited communication may contribute to increased
anxiety for women, disturb the continuity and coordination of care, and lead to
complications and dissatisfaction with the care received (Otte & Costa, 2001).

The nurse providing direct patient care needs to know about the patients’ needs
and previous experiences with health and illness (Jensen et al., 2000). Research
conducted in 2002 by the Johns Hopkins Breast Cancer Survivor Volunteer group
showed that women wanted more extensive pre-operative education about both their
disease and how to manage their illness and treatments. In one nursing study, pre-
operative anxiety fell rapidly with education that was specific about all stages of the peri-
operative process and provided detailed information including pictures of the expected
post-operative recovery (Dooley, 2002). This finding confirms the benefit of
comprehensive nursing care during this experience.

The nurse also needs to know and understand the woman’s individual
experience of a breast cancer diagnosis and her family and support systems. Factors
influencing personal experiences include age, marital status, culture, psychological
coping ability, social network support and relationship with family doctor (if they have
one).

Women diagnosed with breast cancer are confronted with different stressors
throughout the trajectory, i.e. awaiting diagnosis, having surgery, anticipating the
possibility that the cancer has spread, coping with side effects and finally facing the risk
of recurrence (Henselmann, Sanderman, Baas, Smink, & Ranchor, 2008; Coyne, & Barbasi, 2009 & Iwamitsu et al. 2005). Other authors have confirmed that offering only one method of information or support is not sufficient and that a variety of methods and options to present information and support to all the women during this experience is required (Coyne & Barbasi, 2006; Hilton, 1996 & Hutchinson, Steginga, & Dunn, 2006). The range and complexity of women’s needs during the breast cancer journey are unique to each woman and her family. To be effective, nursing care must be tailored to the unique needs of each woman. In order to focus on the unique needs of each woman, the development of the Rapid Diagnosis Breast Health Clinic (RDBHC) requires nursing leadership for program development and evaluation. In addition, special considerations and nursing interventions must be developed as breast cancer surgery is transitioned from being a procedure that has traditionally been done as an in-hospital overnight procedure to one that is carried out as a day care procedure.

The fourth part of this section of the paper describes the author’s beliefs and assumptions regarding nursing care for women during the journey from suspicion of a lesion to treatment for breast cancer. Based upon learnings in previous graduate course work, this section also includes the author’s beliefs regarding the role of an Advanced Practice Nurse.

1.4 Beliefs and Assumptions about Women with Breast Cancer and Advanced Practice Nursing

My beliefs and assumptions about women with breast cancer and the role of the Advanced Practice Nurse (APN) have evolved throughout my undergraduate and
graduate education journey. I have developed an in-depth understanding of the continuum of care for women with breast cancer. The diagnosis of breast cancer initiates a complex process of coping with disease, diagnostics and different therapies. This process includes dealing with physical, psychological and sometimes spiritual issues and participating as a partner in a complex system of medical diagnosis and treatment. Breast cancer is one of the most intensively investigated areas in oncology; innovations are frequent, making breast cancer care a rapidly changing specialty (Eicher, Marquard, & Aebi, 2006). It is my belief that women going through the breast cancer experience and who require day care surgery would benefit from additional supports, health education and information from a professional nurse (RN or APN).

The domains and competencies of APNs are grouped into five main areas (clinical practice, education, collaboration and consultation, research, and leadership), the effective interaction, blending, and simultaneous execution of the skills, knowledge, judgement, and interpersonal attributes in a highly complex practice environment that characterizes advanced nursing practice (Canadian Nurses Association, 2008; Hamric, Spross & Hanson, 2009). The nursing care of women with breast cancer needs to be grounded in knowledge about their illness experiences throughout the continuum of breast cancer care; in addition to biomedical and nursing knowledge and knowledge about local health services. The goal of advanced practice nursing and interprofessional collaboration for this patient population is to promote healing and achieve optimal health (Liebert, Parle, & Roberts, 2003).

APNs are leaders in developing nursing practice and contribute to knowledge development for the discipline of nursing. The leadership, mentoring and role-modeling
skills of an APN are unique in their contributions to the enhancement of evidence informed and theory guided nursing practice (Loftus, & Weston, 2001). Historically, APNs have been successful in changing the traditional power relationships and have broadened professional boundaries to become expert clinicians and patient centered decision-makers. APNs with clinical expertise are in a position to demonstrate their competencies to mentor, teach, and support practicing nurses improving the nursing care provided to greater numbers of women (Donnelly, 2006).

As an APN, I will advocate for program structures and practices that support time for individualized nursing assessment, answering questions, and an opportunity to discuss any necessary preparations for treatment and recovery that patients may require (including identifying health inequities). The blending of APN competencies will contribute to the advancement and improvement of breast cancer planning and development as well as improve direct nursing care through a range of clinical leadership and professional activities.

The goal of Fraser Health is “Best in Health Care.” In order for this statement to be actualized, the patient must be at the center of all aspects of the care continuum. Nursing must embrace a foundation of respect, human dignity and enact the belief that the patients are the expert regarding their own lives (Nelligan et al., 2002). The patients must be provided with the tools to manage their care in collaboration with the health care team. The APN has the knowledge and skills that centers on caring relationships that promote health and quality of life from the patients’ perspective. The role of an APN and the interaction with the patients and their family members has the potential to change their experiences, promote healing and improve health outcomes for this patient
population. The next section outlines in detail the approaches implemented to complete this project.

**Part 2: Approach to Project Inquiry**

Part 2 of this paper answers the questions related to “how” the project purpose and objectives were achieved. A rigorous approach to the inquiry was implemented to carry out the project. The approach to inquiry included the following steps: a comprehensive review of the literature related to the experience of women with breast cancer; personal observations and reflections on accompanying three women on their breast cancer surgery journey at SMH; and the identification of gaps in nursing knowledge and practice during the diagnostic and surgical phases of the breast cancer journey. Each of these topics are described in detail in the sub-sections of Part 2 of this paper.

**2.1 The Experience of Women with Breast Cancer: A Literature Review**

This section provides a thorough and comprehensive review of the literature related to the experience of women with breast cancer who undergo day care surgery. A literature search using CINAHL, OVID, Medline, AMED, British Nursing Index, PsycINFO databases and the Cochrane Library with the search parameters of breast cancer and lived experience or attitudes; breast cancer and day surgery; breast cancer and patient needs; and breast cancer and nursing care was completed.

Although the focus of the search was qualitative research and nursing research on women’s lived experiences during the peri-operative period, many other articles were found that utilized scales to quantify how women felt during this experience. Some of
the scales included the Profile of Mood States (POMS), the profile of Mood States-Short form (POMS-SF), the Life Orientation Test-Revised (LOT-R) and Impact of Event Scale (IES), and the Cancer survivors Unmet Needs measure (CaSUN) to name a few.

In the quantitative studies, women were expected to pick a number expressing how they were feeling. Many of the studies concluded by stating that further research was needed to retest reliability or concluded that there were major gaps in the research due to demographic differences. This leads one to wonder if this gap was due to attempts to score emotions and feelings instead of using a qualitative approach and listening carefully to what the women said. The gaps noted in the research due to demographic and cultural differences are of concern due to the multi-cultural nature of the communities we live in. Transcultural research about women’s breast cancer journey is very limited. Three articles did discuss different cultures; African-American, rural vs. urban, and Korean (Koopman et al., 2001; Tisnado et al., 2009; Im, Lee, & Park, 2002). These studies were quantitative in design and therefore did not describe the women’s experiences with their breast cancer journey.

There is a wealth of literature showing that breast cancer patients suffer emotionally and psychologically, but few have investigated the effects of treatment from the perspective of women (Crockford, Holloway, & Walker, 1993; Polinsky, 1994). In writing of breast cancer, Bredin (1999) stated, “Despite the wealth of literature…there have been few studies…directly quoting a woman’s private perspective; how in her words she experiences her changed body” (p. 1113). Lovelys and Klaich (1991) concurred, suggesting that women’s concerns ought to be addressed as women describe them, not following more clinical models of research.
A few qualitative studies have emerged in response to critiques of biomedical approaches. Researchers have tended to focus on singular issues, such as breast loss, lymphedema, and menopause (Bredin, 1999; Carter, 1997; Davis, Zinkland, & Fitch, 2000). Dow and Lafferty (2000) have suggested that women experience changes in quality of life and psychosocial adjustment that might not be observed readily in clinical practice settings. Loveys and Klaich (1991) wrote, “Illness demands are experienced in every aspect of a women’s life, including her identity, daily routines, family and social experiences and her perception of the past, present, and future” (p.75). Taken together, these findings can contribute much to knowledge about the complexity of life during the woman’s breast cancer journey.

Only the women themselves can describe how they experience living with newly diagnosed breast cancer and treatment. Awareness of women’s experience of their new and changed life situation is vital for supporting their adaptation to this health crisis. Nurses can help women and their families to fully understand their current health situation, participate as a partner in care, and navigate a complex health system. The needs of female breast cancer patients throughout the course of the disease are largely related to physical and emotional well-being, social support, spiritual well-being, quality of life and understanding the healthcare system. However, these needs change with the disease trajectory and are influenced by patient characteristics and environmental factors (Girgis, Boyes, Sanson-Fisher, & Burrows, 2000; Hoskins & Haber, 2000; Lindop & Cannon, 2001; & Wang, Cosby, Harris, & Liu, 1999).

Understanding the needs of women who are breast cancer patients is the first step in knowing how nurses can better assist women and their families to fully
understand their health situation, participate as a partner in care, and navigate a complex health system. For the purposes of the literature review, women’s breast cancer journey has been divided into four main sections: diagnosis; treatment (up to immediate post operative time period); support systems, and needs expressed throughout the journey.

2.1.1 Diagnosis

Discovering a lump in one’s breast is a frightening experience for many women. The confirmation of the cancer diagnosis confronts women with the fact that daily life is no longer a matter of course (Hoskins & Haber, 2000; Ambler et al., 1999; Bickell & Young, 2001; & Castellanos et al., 2008). The diagnosis of breast cancer conjures feelings of fear and uncertainty and threatens a woman’s very existence. Breast cancer irrevocably changes the lives of women who have been diagnosed with the disease. Women experienced a precipitous transition from a “state of wellness” to a “state of illness” almost overnight after finding lumps in their breasts or receiving mammogram results. Landmark & Wahl (2002) found that when women’s total existence is threatened; a tenacious attitude in the form of willingness to live becomes mobilized. The will to live was related to experiences connected to the future, to close relationships, to changes in regard to what is important in life, to belief and doubt, and to fear the loss of important relationships. The women in Landmark & Wahl’s study appeared to activate unknown strengths in their fight against death, as one woman stated: “There is more between heaven and earth, something that’s pulling the strings, so maybe that’s why I keep holding on” (pg 115).
A study by Salander (2002) quoted a women’s experience of how her suspicion of breast cancer was confirmed: “The doctor left the room. The nurse hugged me and asked if I had been expecting to hear what I had just been told. She said that I could stay for a while and then she left the room, too. There I am, ALL ALONE, in despair, the tears falling down my cheeks, everything was awful….I felt so extremely small and abandoned when they both just left the room” (pg 100). The diagnosis of breast cancer triggers strong emotional reactions for women; these reactions can be interpreted as a traumatic crisis (Landmark & Wahl, 2002). The words “you have cancer” release a torrent of concerns about the future, the treatment ahead, and the consequences for their families.

Women with breast cancer experience emotional distress and mood disturbances, such as anxiety, confusion, depression, worry about recurrence, and a decreased sense of well-being (Blume, 1993; Brandt, 1996; & Longman, Braden, & Mishel, 1999). Anxiety has been defined as a reaction to a threat, and cancer is a very serious threat to a person’s well-being and to life itself (Sheppard & Ely, 2008 & Schmid-Buchi, Halfens, Dassen, & Van den Borne, 2008). The diagnosis of breast cancer is experienced as causing acute emotional imbalance and influencing the women’s ability to manage their everyday lives. “Cancer is like a crab, it creeps along and eats away my flesh and my life” (Skott, 2002, p. 231). The lifelong consequences of breast cancer need to be recognized, addressed, and treated so women can heal and adapt to the new “normal” of living alongside a breast cancer diagnosis.

During the time of diagnosis, women and their families are given a plethora of information about the disease process and are often called upon to make immediate
decisions about treatment choices, some of which can have lasting effects on their lives. Many of the studies identified in the literature focused on symptoms and symptom management (add citation). However, few studies have explored women’s experiences and perceptions during the various treatment regimes, and fewer still have focused on how an Advanced Practice Nurse might promote healing and wellness for these women and their families.

Many women with a diagnosis of breast cancer were previously healthy; they may have never undergone any type of surgical procedure or have been treated with drugs or radiation that have significant side effects. Women are thrown into a whirlwind of frequent visits to physician offices and clinics for treatment. One woman described the diagnosis and treatment experience as an “erasing of a former self” because of physical and emotional alterations (Boehmke & Dickerson, 2006, p.1123). Healthcare providers need to be aware of what hearing the word cancer means to a woman and how the diagnosis of breast cancer precipitously changes a woman’s life and functioning.

2.1.2 Treatment

Treatment for breast cancer involves physical changes including the loss of breast tissue, changes in digestion, and alterations in skin and mucous membranes. Even though lumpectomy and sentinel node biopsy (SNB) are considered to be less invasive than a mastectomy, women have stated that the change they experienced because of surgery affected not only their body images, but how they viewed themselves as a woman. As one woman related: “I looked in the mirror and said, ‘What
happened to you?” (Boehmke & Dickerson, 2006, p. 1123). Other women viewed themselves as “being cut up, disfigured, clothes don’t fit right”. The surgical procedure altered their familiar body reflections, leaving them with a loss of normality and a wish for improvement (Boehmke & Dickerson).

Loss of a breast can result in changes in the women’s perception of her own body, changes in the way she experiences and understands herself, and changes in her experience and understanding of relationships with other close relatives. The breast is often linked to femininity and loss can give rise to feelings of degradation in relation to the opposite sex. If the loss of her breast results in changes in the woman’s self image, so that she dislikes, or is unable to tolerate herself, the experience of femininity is affected (Bredin, 1999).

A desire to hide the loss of a breast was an aspect that came to the forefront once research focused on the woman’s perspective rather than medical treatment. In some situations women found the use of a scarf helpful to camouflage the loss. In other situations, however, it was not possible to disguise the loss, so women chose to hide themselves. Breast prosthesis camouflages the loss of breast tissue but results showed that all the women were concerned about using prosthesis. “I sometimes use a scarf so that it doesn’t show” (Landmark & Wahl, 2002, pg 117). Women have differing opinions about breast reconstruction, and there is evidence that their opinions changed over a period of time (McPhail & Wilson, 2000 & Simpson et al., 2007). Many women are asked to decide about immediate breast construction in the same office visit when they are told they have cancer and will require surgery. This request for such a significant
treatment decision adds further to the distress these women find themselves in at that moment in time.

Day care surgery has been identified to have both advantages and disadvantages for patients and their families. The practice has been widely implemented for many surgical procedures in most developed countries, including Canada. With the advent of day care surgery, patients experienced less contact with health care professionals both before surgery and in the initial postoperative period. The admission process and physical preparation of patients take the majority of preoperative nursing time, leaving minimal opportunity for education, reinforcement of effective self-care strategies, and emotional support following surgery (Sladek, Swenson, Ritz, & Schroeder, 1999). It is important for nurses, in the role of patient educators, to provide useful and appropriate information to the patients in their care. This applies equally to other health care professionals, and a multi-disciplinary approach to health care is essential. The provision of information can be complicated in the hospital environment because of limitations on time available for health teaching and the woman's readiness to learn. Knowledge of what the woman really wants and needs to know should make information giving a more effective and worthwhile process.

In the study done by Margolese & Lasry (2000), women identified recovery and psychological adjustment as the main advantages of day care surgery. These women returned to their normal life and everyday activities, including work, about a week and a half earlier than patients who were hospitalized. The women stated the early discharge tended to bring the family unit together and it “downgraded the seriousness of the operation” (Margolese & Lasry, 2000, p. 186). The women expressed a high degree of
satisfaction with their surgical experience; it made them feel that they had control over
the progression of the disease, and lead to a faster recovery without the assumption of
the sick role (Kambouris, 1996; Pedersen, Douville, & Eberlein, 1994 & McManus,
Topp, & Hopkins, 1994). During the first week after discharge 50% of the women called
the hospital seeking advice on how to manage pain, to report problems with their
dressing, and seeking additional information about further treatment. Many of the
women who phoned seeking advice on how to manage their pain did not take their
medication as prescribed. The patients were very reluctant to take analgesics, revealing
a possible gap in their post-operative pain management teaching and the ability to learn
these new concepts during the immediate post operative period (Marchal et al., 2005).

In the studies about day surgery and breast cancer, patient demographics
included age, years since menopause, marital status, education, occupation, time since
surgery, and social network. There was no mention of cultural origins. Moreover, there
is limited research done on the meanings of breast cancer among Asian women, but
the studies I read indicated that prevalence of psychological morbidity is substantially
higher for Asian women when compared to Caucasian women (Ching, Martinson, &
Wong, 2009; Im et al., 2002 & Lam, Chan, Ka, & Fielding, 2007). Unfortunately no
studies were found in English publications regarding women with breast cancer from
other cultures such as the South Asian and East Indian population. Given the high ratio
of South Asian immigrants in the community of Surrey, such information would be of
value to Fraser Health and other communities.

When women have recuperated from surgery, the next phase of their care may
include chemotherapy and or radiation. During chemotherapy and radiation women
described feelings of total exhaustion. Some of the words used to describe their feelings were: drawn, knocked out, indisposed, foul, unwell, miserable, fed up, depressed, bad, rotten, strained, enough is enough, tough, and worn out (Stephens, Osowski, Fidale, & Spagnoli, 2008). Quotations from women have shown the suffering worsened as the treatment progressed: "Nausea is one thing, and then there is everything else. You’re in constant turmoil, it’s exhausting, and you feel like an empty shell. But things are at work inside you—it’s as if you’ve got lots of workers inside you" (Stephens et al., pg. 256). As women face the diagnosis and treatment of breast cancer, nurses need to appreciate that women endure more than physical symptoms. Healthy women have had their worlds transformed and oftentimes shattered. Women’s lives are altered physically and emotionally.

### 2.1.3 Support Systems

Concern with loss of former self and body image changes during the breast cancer experience may cause a change in personal relationships. Blakewell and Volker (2005) described how breast cancer affects personal identity, self-esteem, self-efficacy, and relationships and partnerships. Support from close family members is described as important, and it is here emotional aspects are most apparent. Jacobsen (1986) supports this by pointing out that where serious illness occurs, patients primarily need emotional support to maintain their self-respect and their belief that others will provide help.

Other studies have also found that women with breast cancer state that sympathy and compassion from their support network provides comfort and security
(Paalsson & Norberg, 1995; Lugton, 1997 & Coward, 1998). Results showed that some women were uncertain as to how they could communicate with others, especially their closest relatives. Social support in the form of “nearness” was often described as important and social support received from husbands and children appeared to enhance the women’s willingness to fight against the disease. “My friends keep an eye on me; I’ve a lot to thank them for. A network means a great deal. When you’re alone with everything, you can’t manage to carry the weight alone” (Paalson & Norberg, pg. 260).

Individuals draw on different coping strategies during the treatment period so it is important for health care professionals to consider and respond to individual and family needs. Research has identified the importance of the family working together to overcome the problems associated with treatment schedules (Clark, 2002). Health care professionals must note the importance of understanding family strengths and networks to ensure the caregiver support network does not become stressed and unable to provide vital support. A multidisciplinary team approach is essential to ensure women and their family members can access counsellors, social workers and other support professionals for assistance when needed. The assistance required by these women may be for child care, home making, a drive to an appointment, or just to have someone be with them.

Nurses can encourage women to voice the demands that diagnosis and treatment have placed on their lives. Wounded physically and emotionally, women must express how they feel and they must be heard. Patient-centered communication and adequate time must be offered to these women so that they can voice their fears, needs and concerns.
Unfortunately, results from the Landmark, Strandmark, & Wahl (2002) study showed that many women experienced a lack of support and information continuity particularly when receiving health services. Lack of support from nursing staff was experienced as an extra burden for some of the women and often appeared as lack of continuity in treatment follow-up. Waiting time was difficult and routines for follow-up were unsatisfactory. The time prior to hospital admission was characterized by several women as a constant battle against their fears and the hospital systems (Landmark, Strandmark, & Wahl, 2002). They had to be on alert and fight for themselves by calling to check appointment times and asking for necessary information. A specialized nursing role within a Rapid Access Breast Clinic has been shown to contribute to an improvement in health and well-being of women with breast cancer, both on physical and psycho-social levels (Eicher et al., 2006).

2.1.4 Information and Support

A great deal has been written about the role of the nurse as a patient educator or teacher and provider of patient support. The emphasis on patient teaching in the nursing literature has focused on the process of education, rather than on the content (Luker, Leinster, Owens, Degner, & Sloan, 1995; Luker & Caress, 1989; Redman, 1993). The assumption has been that nurses know what patients need to know, and have the necessary information to share with women. Similarly, little attention has been given to what patients and individuals want to know and what their priority information needs are (Liao, Chen, Chen, & Chen, 2007). Information giving is an essential element in making partnerships effective. In order for people to feel comfortable participating in decisions about health care, it is important that they are adequately informed. Hence,
the type of information an individual has access to may be the key to the process of empowerment. Health care providers arguably have a responsibility to provide individuals with the most accurate and relevant information needed for informed decision making. Information is a necessary prerequisite to informed decision making, can aid coping, and lower anxiety and distress (Cawley, Kostic, & Cappello, 1990; Cooley, Moriarty, & Berger, 1995; Luker et al., 1995; Bilodeau & Degner, 1996 & Hagopian, 1996).

The concept of support in the nursing literature has been defined as “the provision of information, help, and emotional comfort to enhance coping and feelings of empowerment, make better health-related decisions, minimize distress, and promote health, self-care, and appropriate use of health services” (Stewart, 1995, p. 99). Supportive care also includes the provision of health teaching, and health information, clarification of information as necessary, and participation in clinical discussions to ensure an informed decision regarding care is made while having the patient at the centre of care. Information and support are both well documented needs in the literature for women with breast cancer.

Women with breast cancer have substantial needs for information. The disease, however, affects not only women themselves but also members of their families. It is not surprising therefore that the family members of individuals with breast cancer also have substantial learning needs (Krisjanson & Ashcroft, 1994; Hilton, 1996; Carlsson, Strang, & Lindblad, 1996).

It’s very difficult making treatment decisions because of the contradictory information, and it’s very difficult not being a medical person. It was the woman in
the end who helped me decide. She didn’t try to persuade me, but it was something about the reasons she gave, you know, regretting not doing it in the future if I get cancer again. Secretly I think I knew was going to do it (have chemotherapy), and I didn’t want to find out too much negative information. (Krisjanson & Ashcroft, pg. 15).

Too much or too negative information can be overwhelming for some women.

Research has shown that an initial visit and follow-up telephone call can be an effective tool for assessing the multidimensional needs of women with breast cancer (Stephens et al., 2008). Furthermore, the nurse who has already established a relationship with the women should conduct the telephone calls because she can interpret and react to the patients’ responses and offer further information to her.

2.1.5 Analysis and Discussion

In the literature review, I learned that the needs expressed by women with breast cancer relate to their physical, psychosocial and spiritual well-being, as well as to their health-related quality of life (DeGrasse & Hugo, 1996). The women experience different needs at different cancer stages, such as the diagnostic, treatment, follow-up and recurrence phases. These needs change over time and are influenced by demographic characteristics, personal experiences of breast cancer, family structure, material resources, social support, and culture (Hoskins & Haber, 2000 & Girgis et al., 2000). This finding affirms that health care providers must be holistic in the approach to care, while keeping in mind the need to individualize each woman’s needs and address these needs throughout the continuum of care. Helping the women in our care to achieve balance and understanding throughout their disease trajectory will provide opportunities to facilitate positive outcomes for all the women (Stephens, et.al., 2008 & Denton, 1996).
Understanding needs should be considered in the development of a program of woman centred care that includes appropriate and understandable educational materials and support systems that promote healing and a return to normal functioning for women with suspected breast cancer and their families. Women and their families need established consultation and communication channels to clarify doubts and express concerns, thus helping them cope with psychological distress during their journey (Luker et al., 1995). Understanding the needs of the women and their families can improve nursing practices and contribute to disciplinary scholarship in nursing. Sharing this information with other healthcare providers can also contribute to woman centred care both before and after day surgery.

Searching the literature also helped identify several questions for further inquiry. These questions are: “Are the women at the centre of our care? Are the women working with the health care professionals to create a plan of care that is individualized to their needs?” If women are at the centre of care will we meet their needs throughout their trajectory of care, from suspicion to treatment of breast cancer?” I also wondered about women’s perspectives of their breast cancer journey. The next section of this paper describes my personal experience observing and providing nursing care to three women who had breast cancer surgery at SMH.

2.2 Personal Reflections from Providing Nursing Care for Three Women with Breast Cancer During Day Care Surgery

The next step to meet project objectives was to provide nursing care for three women who underwent breast surgery at SMH as outpatients and reflect on my
experiences to confirm or refute learnings from the literature review. This section will offer personal reflections and analysis of what the women told me about their experiences. Similarities and differences from the literature will be reviewed in comparison to reflections on accompanying the women through the day surgery phase of their breast cancer journey. This reflection will include a discussion of the needs for nursing support for the patient and her family prior to surgery, during the surgical experience and after discharge from the hospital.

The first step was to identify women who were being scheduled for day surgery. Following meeting with the surgeon, we agreed that I would provide nursing care for three women during their day care surgical experience for breast cancer at SMH. We agreed on a process regarding how I was to be notified about the patient’s scheduled day care surgery. I was called by the Operating Room (OR) booking office after the surgeon had booked the patient for the selected procedure. I contacted each woman by telephone and made arrangements to meet her at the pre-admission clinic within the week. I met her the morning of surgery at the surgical admission department and stayed with her pre-operatively. Following the actual surgery and post anaesthetic recovery period, I stayed with her post-operatively until she was ready to leave the hospital. I called each woman by phone the day after surgery and one week after her discharge. My goal in each case was to hear from each woman about her experiences throughout the course of her surgical treatment and identify her needs for nursing care.

The first woman I met was Janine (a pseudonym) a 63 year old English speaking Canadian homemaker, who has been married for many years and currently lives with her husband Matthew. She described herself as “healthy as a horse” and who “is a very
good patient”. When asked why she was a very good patient her reply was that she takes vitamins, gets lots of rest, has a yearly physical examination and performs monthly self breast examinations; “all the things you are told to do – to remain healthy”.

Janine discovered a lump while performing her monthly breast examination, waited two months before going to see her family doctor, and then spent the next four months going for further tests. She described the tests as “disruptions to her daily living.” During the months of testing Janine slowly shut herself off from her husband and the supports she may have had through her church group, describing herself as preferring to be alone. Janine refused her first date for surgery so she and Matthew could go on a planned vacation. She later told me “I thought this would be our last good vacation since I had the “C” word.” Two months later, Janine told her husband she had a small feminine problem and went to see the surgeon. She was booked for surgery the next week with another test to be done the day before the surgery. The surgeon’s office called me requesting me to see her in medical imaging since she was having surgery the following day and she did not attend the pre-admission clinic. Janine refused to participate in pre-operative teaching and would only participate in social chit chat. She told me that she trusted the doctor to do the best thing for her and that she did not want people meddling in her business.

I met Janine and her husband Matthew in surgical admissions the next morning. Matthew had just learned about his wife’s surgery when he found the information she had received from the surgeon. He was very distraught wondering if Janine was going to die, wondering why she would hide this from him and what the next steps in her care would be. Matthew had many questions and appeared to be taking over Janine’s care.
made contact with them the day after discharge and although Janine had some questions for me; it appeared she was starting to accept what was happening and was beginning to participate in her care.

The second patient I observed was Pat, (a pseudonym) a 57 year old, high school teacher with two daughters who are both married and live locally. Pat was busy “doing life and taking care of business.” She had gone for her screening mammogram and had not noticed that she never received the letter from the Screening Mammography Clinic telling her that her mammogram was okay and to have a repeat screening in two years. Her family doctor called her and told her there was something funny on the mammogram; she was booked for a repeat mammogram two weeks later. She was referred to a surgeon and at this point realized there was something wrong. Her test results were not available for the surgeon and Pat became very angry at her family doctor for not sending them to him. The surgeon sent her for further testing and these tests confirmed breast cancer.

I met Pat and her daughters at her pre-admission clinic visit and Pat shared some of her story with me. She told me how hard it was for her to think about what to do; she could not carry out the simplest of tasks. She is a high school teacher and she could not concentrate enough to read the information she received from the surgeon and had to write everything down or else she would forget. On the day she had surgery she was a different person. She was calm, in control and was asking the questions that she did not ask in the pre-admission clinic. Her immediate post-operative period went well and she described herself as doing well, up and about, and laughing with family and friends.
The third patient I observed was Lui, (a pseudonym) a 43 year old woman who was married with three children (ages 18, 15 & 8). Lui was a homemaker and of Korean descent. Her prognosis was very poor due to the late diagnosis of her breast cancer. She never sought out healthcare for herself until her family doctor sent her for a screening mammogram. The diagnostic period took five months and she was booked for surgery within 1 week of diagnosis; therefore she did not attend the pre-admission clinic.

I met Lui on surgery day. She was all alone, looking very sad and scared. Prior to her discharge she slowly brought up some of her concerns. She blamed herself for having cancer. She wondered what she had done to get cancer and if she had exercised enough. I called her the day after surgery and she was trying to care for herself and her home without supports. I met with her after her check up with the surgeon to answer some of her concerns and to explain the care she would be receiving next.

In this section I have provided a brief summary of my observations and dialogue with three women who underwent day care surgery for breast cancer at SMH and their family members. I was privileged to share their personal experiences and their stories.

The next section shares my personal reflections about the women’s breast cancer surgical experience including comparisons and contrasts with findings from the literature review.
2.3 Reflections on Accompanying Three Women on Their Breast Cancer Surgery Journey at SMH

In this section I will share my personal reflections about the journeys of the three women I observed, share my learnings from each of these women, and compare and contrast their experiences with findings from the literature review. During my scheduled observations, it was my intent to focus on the women’s day care surgical experience. I soon found that the women could not separate their surgical experience from their breast cancer journey. They looked upon the entire trajectory from suspicion of breast cancer to surgery as one long event.

There were many project learnings from my opportunities to observe and talk to Janine, Pat and Lui. Prior to meeting these women I thought I knew and understood the needs of women with breast cancer, i.e., for information and support. What I was not prepared for was how and when the women want this information, what support they require from the health care team and how the health care system impacts their journey. Sharing the journey with these three women has given me a deeper understanding of what information needs they have, when and how to provide the information, and what support means to them.

Janine kept her secret of breast cancer to herself for over seven months. My greatest learning from Janine was a better understanding of the power of fear and denial. Fear and denial had taken over her life for almost ten months. These emotions appeared to paralyze her. Denial caused her to delay seeking treatment and quite possibly put her life in grave danger. She did not ask for information; she chose not to
participate in her care and decision making until the day after surgery. Another learning from Janine was the importance of support from family and the health care system. When Matthew discovered the secret he became an active participant in her care. He was ready for information and support before Janine was. In essence he became another patient. He became the link from the health care system for information to Janine. This family taught me the importance of caring for the patient and their family as one inclusive unit.

From Pat I experienced two major learnings. Pat is a woman who is used to being in control. When she was not in control of her own life she became angry and easily overwhelmed. This negatively impacted her ability to make decisions. I learned from Pat the importance of having the patient at the centre of care and to let each patient lead the way in their care with information given at key points along the way. My second learning from Pat was related to informed consent. She described to me that in the surgeon’s office she signed her consent for surgery, but she had no recollection of what she was told or what she consented to. I now question the ethics of having someone sign their consent for surgery when they are emotionally distraught having just received very bad news. Decision making at this point regarding surgical intervention can be highly impaired.

My learning from Liu was about the importance of understanding culture and working within the beliefs and values of each patient’s culture. I returned to the literature to more fully understand Lui’s experience. I learned that in Korean culture, breasts mean positive things to women, including generosity, good luck, and good things from God (Kim, 1998 & Shin, 1995). Loss of a breast consequently means bad luck to Korean
women and their family members, and breast cancer is perceived to be caused by worries, anger, and psychological distress rather than other risk factors (Shin). The negative meanings of breast cancer were reported to make Korean women not try to survive or be active in their cancer treatment process and contribute to feelings of depression and helplessness (Im, 2000).

Traditional Korean medicine emphasizes that “negative attitudes” lead to “negative behavior patterns” and that people have cancer because of their misconduct or negative attitudes (Im, 2000). Korean women are prohibited from discussing bodily experiences such as menarche, sexual intercourse, menstrual health and menopause and many do not use direct terms when referring to their breasts but used vague terms such as “this” or “that” and rarely expose their body parts in public (Im). The blame intertwined with the modesty that is prevalent in Korean culture has the potential to cause Korean women not to seek medical care in a timely manner. When I compared the literature with my experience with Lui the cultural influences became very evident. She blamed herself for having cancer because she did not exercise enough or because she was not a good wife, she was very shy and did not make eye contact or ask questions. She did what she was told. This information reinforces the need to have the patient at the center of care. It emphasizes the importance of individualized patient assessments within a cultural context (Rosser, 1994).

My clinical observations have led to further reflections on the role of the Advanced Practice Nurse (APN) and how an APN can contribute to optimal health outcomes for women with breast cancer. To achieve this goal the APN in conjunction with the patient would identify the multiple physical, psychological, social, sexual and spiritual needs of
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the women throughout the continuum of breast cancer care. Once the woman’s needs are identified, the APN would facilitate a collaborative approach to care planning, implementation and evaluation by ensuring the patient and the multidisciplinary team are working effectively as a team and that they have established secure and dependable relationships to meet the woman’s needs. A collaborative approach to care will create a plan that is flexible and responsive to changes in the patient’s needs throughout her continuum of care. The APN will ensure the health and support services needed are delivered in a timely, flexible and efficient manner to avoid a delay in diagnosis and treatment and to decrease the anxiety of the patient during this period of time.

The APN will provide comprehensive, specialized and individualized information to the women about the pathophysiology of breast cancer and its effects, treatment approaches, and self-management strategies, using evidence-based educational strategies that are consistent with individual clinical circumstances, preferences, information and self-care needs (Yates et al. 2007). With the patient at the centre of care individual needs will be illuminated and health care professionals can work with each patient to meet their individual needs.

The next section will compare and contrast the experiences of Janine, Pat and Lui during the diagnostic phase of their breast cancer journey with findings from the literature review and identify gaps in nursing knowledge and practice.
2.3.1 Nursing Care Needs During the Diagnostic Phase of the Breast Cancer Journey

The process of undergoing investigations for a breast abnormality can cause significant anxiety and stress in patients. Research has shown that during the diagnostic phase women may need health teaching regarding breast investigations, listening to their fears, and providing understanding and reassurance that the diagnostic tests that are required will be completed in a timely and efficient manner. Nurses and other health care professionals must remain vigilant to ensure that the needs of the patient are being addressed in an individualized manner and that no assumptions are made as to what type of information they require or what type of support they request. In the previous section needs for social support, information, coordination of care, and timely diagnosis were identified.

According to Chappy (2004); O’Mahony (2001) and Freedman (2003) women with suspected breast cancer ranked their most important physical needs as careful examination and accurate diagnosis, tests offered as soon as possible, and being informed of the results as soon as possible. The informational needs of women immediately after diagnosis were concerned with the likelihood of cure, the spread of disease and the treatment options available (Luker, et al.1995). The diagnostic phase is conceptually different from other stages of the breast cancer experience, in that it forms an interface between suspicion and confirmation of health or illness status (Poole, 1997). Health care providers must be sensitive to women’s reactions to a diagnosis of breast cancer, in order to determine and respond appropriately to their needs. During this time period women have long gaps of time between tests and many of them have
been given reassurance that the testing is a matter of being careful and not to worry. As a result of the reassurance given, many of the women do not look for more information as the diagnosis is not yet a reality. This time is spent going from test to test, waiting for results and waiting for confirmation. This time of uncertainty would be a good time to build relationships with the women and provide information in small pieces along the way.

Pat, Janine and Lui each reacted differently during their journey. Only Pat sought out information once she saw the surgeon and none of these women sought out information during the suspicion period. Janine demonstrated a sense of denial or a need to avoid confirming the “diagnosis” in order to go on living. Pat was simply taking care of her routine health care needs, and Lui appeared to be all alone to fight this battle. Her culture dictated how she should act, and what she should do. She did what her doctor told her and never asked any questions. These three women illustrate that the educational and emotional needs of women with breast cancer vary and evolve over time and justify the need for several contacts with a health care provider as they progress from suspicion to diagnosis to treatment. Chappy (2004), O’Mahony (2001) & Freedman (2003) reported that women needed the assistance of healthcare staff to make appointments and remind them prior to the next visit, probably because they were worried that they might forget the appointment and delay getting their diagnosis. Two of these women began their journey at the screening mamography clinic and the third women felt a lump and sought out medical care. All were then processed through the diagnostic phase by their family doctor. Pat became very angry at her family doctor
when her test results were not sent to the surgeon; she questioned the continuity of care she was receiving.

The care of women with breast cancer varies across the globe. In the United Kingdom breast cancer care was found to be fragmented, inefficient and affected by the variety in physician practice patterns and treatment options offered to women leading to a high mortality rate for this patient population (Chouillet, Bell, & Hiscox, 1994 & Poole, 1996). It was out of this concern that the European Society of Breast Cancer Specialists (EUSOMA) was formed. This group of specialists have chartered the course of care for women throughout Europe with guidelines and indicators to measure to ensure appropriate, consistent care. The EUSOMA model of care is considered by many to be the “gold standard.”

In 1992, a joint task group formed in Montreal consisting of the Canadian Cancer Society, the National Cancer Institute of Canada, the Medical Research Council and Health Canada with a mandate to create a similar coordinated strategy in breast cancer care and management to minimize the delay in diagnosis and ensure consistent guidelines for care of this vulnerable population of women. Unfortunately, participation in these initiatives is voluntary, thus creating variance in care women with breast cancer receive across Canada. As a patient comes in contact with others who have a personal experience with breast cancer, a well meaning friend, or a family member who is the healthcare field, they may receive advice or learn about inefficiencies of the system and may begin to realize the course they have travelled may not meet the “gold standard” established in countries outside of Canada.
The diagnostic period ranged from 4-6 months for Janine, Pat and Lui which far exceeds the EUSOMA standard of 3 weeks. There is considerable evidence that an abnormal breast screening result can precipitate acute anxiety (Olivotto et al., 2000). Pat, however, did not experience her anxiety until she saw the surgeon. Janine did not express anxiety but her delayed surgery could have resulted from an acute anxiety reaction; and Lui fulfilled her role as a Korean woman and did not exhibit any outward signs of anxiety. None of these women questioned the length of time it took to receive a diagnosis or questioned if they were receiving the correct tests. I wonder if they assumed this is how the health care system works and simply trusted their health care providers. It would seem that women need assistance navigating the health care system so that they can receive care in a more timely way.

Literature has shown that women who were married or had children expressed a higher level of need for emotional support (Lindop & Cannon, 2001). I wonder if this is due to them having the concerns of another person to think about; a sense that both the woman and her husband and family were battling with the cancer together as a shared experience. Janine, Pat and Lui all had support available to them from a husband and or children but Janine never shared her experience with her husband until he figured it out the night before surgery. Pat utilized her children as support once diagnosis was confirmed and Lui appeared to be on her own for this journey.

My experience with these differences in the support network of these three women demonstrated that there must be a continual reassessment of the patients needs throughout the diagnostic journey to ensure they receive the information and support they need and can assimilate at the time. The next section will compare and contrast
the experience of Janine, Pat and Lui during the surgical phase of their breast cancer journey with findings from the literature review and identify gaps in nursing knowledge and practice.

2.3.2 Nursing Care Needs During the Surgical Phase of the Breast Cancer Journey

The information and support needs of these women varied throughout their journeys. Once the diagnosis is confirmed health care providers expect the women to be involved with the decision making for treatment. However, having just received a confirmed diagnosis, women are frequently in a state of fear and shock. It is usually at this point the woman sees a surgeon and they are given literature to refer to in order to answer questions. The options for surgery are explained, and questions about immediate reconstruction are asked. One of my patients told me as she was sitting in the surgeon’s office that she could see his mouth moving, but she could not hear anything that made sense. According to research women generally felt that they had not been offered a choice of surgical treatment. It appears that many health care professionals assume women would prefer to avoid a mastectomy and have breast conserving treatment (McPhail & Wilson, 2000). However, further research has shown women prefer having a mastectomy instead of breast conserving treatment due to fear and inconvenience of radiotherapy, along with their perception that survival would be diminished if a mastectomy was not done (Tate, McGee, & Hopkins, 1993). In the past five years there has been an increasing number of women choosing breast conserving surgery, and I wonder if this is due in part to having women more involved in treatment decisions or if this could be a result of physicians who encourage women to choose
breast conserving surgery (National Breast Cancer Centre’s Specialist Breast Nurse Project Team, 2003).

At the surgeon’s office visit, women are often asked to sign consent for surgery. I wonder about the validity of consent obtained at this point in time. Do the women understand what is going to happen to them, are their questions being asked? SMH is considering having interdisciplinary rounds with the women present to discuss her case. This sounds good to me as a health care provider, but I am concerned that the women may find this overwhelming or intimidating, especially if they have not had contact with any of these providers prior to the meeting.

Janine, Pat and Lui were not offered a choice of surgical treatment. The decision was made for them by the surgeon. The treatment of breast cancer is multifaceted and takes time to process. Did the women have enough time to process what they have been told and to ask their questions? Janine, Pat and Lui told me even though the surgeon provided details for them; they could not process the information so questions were not asked. Pat searched the internet and talked to friends and family who had breast cancer to have her questions answered. Janine and Lui deny seeking more information. The internet is not the best information sources for these women but who is their link for accurate information at this time? The lack of a consistent, coordinated journey has altered the care these women should have received.

Janine, Pat and Lui received the same package of information from the surgeon’s office and two of these women did not attend the pre-admission clinic. Pat described her experience in pre-admission as having nice nurses, they meant well, but talk, talk,
talk. She said that they “asked me the same questions my family doctor, surgeon, and technologists did”. She wondered if healthcare professionals read each others notes. “I could see the surgeon’s report—did she not believe him? It was like a little factory.” This cookie cutter approach does not meet the individual needs of women. Women’s needs for information are highly individualistic, with some women wanting information, others avoiding information, and many women fluctuating between information seeking and information avoiding (Rees, & Bath, 2001).

Pre-admission clinics, (if the patient attends) includes both pre-operative and post-operative teaching. The appointments often result in a very long, stressful day for the patient. Is this the best time to be teaching women about pain control post-operatively or drain and wound care. How do we ensure they know what women need to to care for themselves at home? Further research into the role of pre-admission clinics and the effectiveness of current teaching practices would be indicated. Nurses whom the patients may encounter throughout their journey need to take into consideration the information-seeking behaviors of women with breast cancer when providing them with information about the disease and treatment choices. My observations confirmed that the current “cookie-cutter” approach does not translate into optimal post operative self care.

Janine was finally ready to address her needs for physical care when she was at home. In her words, “All the things I ignored for months have to be dealt with now.” Her husband struggled to sort through all of her emotional reactions and to separate fact from fiction. In the end, I personally provided post-surgical care for Janine as she asked the hard questions such as “Am I going to die from this? How long will the dressing be
on? Will I need chemotherapy or radiation? Who will take care of me, the surgeon or my family doctor?” Pat required support from me immediately after we met at the pre-admission clinic. While she wanted information, she was simultaneously over loaded when too much information was given to her all at one time. She had support from family throughout her journey and on the day of surgery “when the rubber met the road” she convinced herself she needed to get “back in control.” Before my eyes she seemed to suddenly change and seemed more calm. She changed from being a victim to being in control. By my second phone call one week post-operatively she was up and about with family and friends, exercising and taking care of herself according to the instructions she had been given.

The care Lui received concerned me greatly. Lui required support as soon as the diagnosis was confirmed. However, further delays in her treatment appeared to be the gravest concern to the health care professionals involved with her care. The rush for her to have surgery immediately took away any opportunity for her to have support from health care professionals. I struggled with how much of this scenario is due to cultural differences or my pre-determined ideas of what care, information and support women should receive. The surgeon referred Lui to a hospital that specializes in caring for people of Korean descent for additional post-operative and other cancer care she requires. I am left feeling hopeful her nursing care needs will be better understood and met by a team who is well versed in her culture, values and beliefs. But what happens when such a resource does not exist for women from other cultures? There is little in the literature to provide direction for evidenced based care for these populations.
The surgical treatment period is not the end of the women’s experiences. Following surgery, many women are referred to the Cancer Centre which may lead to further treatment and different healthcare providers. The support women with breast cancer require comes from a variety of sources. I wonder about the length of time that health care providers are involved with the women after treatment. Nurses may be able to provide follow-up care in conjunction with the family physician to promote healing and prevent and detect early signs of psychological problems. This support may be able to be as simple as routine follow up by phone to check in with the women or for the women to have a phone number for them to use when they have questions or concerns.

Health care professionals can meet some of these needs but it is very important that the woman’s social network is mobilized and provided with accurate information about how to help. Screening for women without an adequate support network and providing additional assistance when needed is also critical for ensuring that patient centred care is a “reality” for all women. Providing education to the social network for these women may include directing the women to credible sources for information. For example, it would have been helpful for Pat to be confident that she was getting information from credible sources on the internet.

The women expressed different needs at different times during their journey. Janine expressed a need to ignore what was happening and did not want information until her post operative time period. It appeared she did not want support from her husband until the day of surgery. She did not express a desire to stay in hospital but she wanted Home Health (HH) to provide her with care 24 hours per day in her home. She was unable to process how to take the analgesics or how to do the drain care. Her
needs appeared greatest in the immediate post-operative period. Pat was given false assurances that all was okay for four months. Once she knew she had breast cancer she wanted information and relied heavily on her support network. Lui appeared not to access family or social supports as dictated by her cultural norms. All of these women needed psychological support, but only Pat had a strong functioning support system. Based on my observations, the needs of these three women were for information and various forms of support provided in an individualized manner.

The next section presents a summary of what I have learned from my review of the literature as well as from the observations and conversations with three women during their surgical experience at SMH. Based on my learnings, I have included implications for nursing practice, future program planning and research. I have also identified the potential contributions that an advanced practice nurse could make to improve patient centered care for women experiencing the crisis of diagnosis and surgery for breast cancer.

3.0 Conclusions and Implications for Patient Centred Nursing Care

The overall purpose of this project was to carefully explore the experiences of women with breast cancer who undergo day care surgery and identify nursing care needs. Based on my exploration of day surgery and the experience of women with breast cancer I have learned:

- In 2010 there will be 1000 women diagnosed with breast cancer and 200 women will die from breast cancer within FH.
- The care the women receive varies and many are not receiving care based on best practice guidelines.

- The woman’s experience is a personal journey. Each woman has different needs making every journey different.

- There is limited research on the effect culture has on women with breast cancer

- Women's needs change throughout their journey and the health care system needs to change with the women so their needs can be met.

- Women need assistance in navigating the health care system.

- The diagnostic period is prolonged and fragmented; there is a lack of consistency in the tests ordered and care the women receive.

- Many women are told their diagnosis by the surgeon (during their first visit) instead of their family physician. They are with strangers who don’t know them or how to give them their diagnosis.

- When being given the diagnosis women are in shock and may not hear or absorb what they are being told, and yet they are asked to make decisions about what type of surgery they prefer or the decision is made for them by a stranger.

- Women leave the surgeon's office with a plethora of information about breast cancer; they don’t know what to read or who to call to answer their questions.
Day care surgery for breast cancer procedures limits the time nursing has with the patient and family.

Support from family can be very important for the women and yet often they are not included in care planning.

Little attention has been given to what women and family members want to know and when they want to know it.

Surgical consent is usually obtained at a time when the women are emotionally distraught and their decision making can be highly impaired.

Having an understanding of the culture and working within the beliefs and values of each patient's culture is imperative if the nurses are to provide patient-centered care.

All women who are on the breast cancer journey experience a sudden change in their lives that also affects the people in their social network. For some the journey ends on a positive note with a diagnosis of a benign tumour. For others it is a long and tiring journey that ends with remission, and for others it is the beginning of the end for them.

The needs of breast cancer patients throughout their journey are related to physical and emotional well-being, social support and the health care system (Liao, 2007).

Understanding these needs is the first step in knowing how to support them. The need for information and support is clear but it is personalizing nursing care that will make the difference for the woman with breast cancer and her family throughout their journey.

Research shows that nursing intervention can reduce emotional distress and assist the woman in returning to her normal routine (Allard, 2006). If we don't assist our patients to
meet these needs they will have physical and emotional scars that may be with them for the rest of their lives.

As I reflected on nursing practice I wondered how often nurses have the time to listen to our patients, or to provide the opportunity for the patient to take the lead in their care. Are we now too busy with the tasks we must do to learn what is important for these women? Patient centered care sounds simple, maybe too simplistic; but I observed many instances where the health care professionals were taking care of the patient without consulting the patient. We have taken the patient out of the decision making process. Patients must be provided the opportunity to be in partners with us in making decisions about their care and treatment.

Women with breast cancer or the suspicion of breast cancer need health care professionals to provide reassuring care and a prompt, careful diagnosis. After diagnosis, they require access to professional caregivers to discuss the diagnostic results, treatments, clarify doubts and express their concerns. The women need to be empowered to work with health care professionals to develop a plan of care that will meet their needs (Coyne & Barbasi, 2006). The following section includes implications for professional nursing practice.

3.1 Implications for Professional Nursing Practice

This section will highlight the implications for professional nursing practice during the day care surgery phase of the breast cancer care continuum. Having a new diagnosis of breast cancer has been shown to be a time where critical thinking is
impaired; assimilating health education and participating in decision making are more difficult. Based on the findings of this project, suggestions for nursing practice include:

- Contact the woman as soon as possible with appointment times and to explain the next steps in their journey. Remind women of their appointment times with a phone call as this provides time for questions and assists in building a relationship with the woman.

- After a clinic visit a follow-up phone call with specific questions related to the visit can be effective for assessing the multidimensional needs of the women and her family. Due to the anxiety women experience they may neglect or forget to ask some of their questions. Encourage women to write their questions down so they are answered at the next contact with a nurse.

- Assess the woman’s readiness to learn and her support systems, cultural beliefs and values, personal experiences of breast cancer, and family support network.

- Develop an individualized care plan in collaboration with the woman and family.

- Provide education for the woman and her chosen support person(s) regarding the specifics of the surgical intervention and treatment plan and what she might expect or anticipate on her breast cancer journey.

- Provide various methods of offering education based on differing learning styles. Some women may learn better visually, making DVDs or diagrams most appropriate. Some women prefer investigational internet processing (Eicher et al., 2006).
• Provide information that is tailored to the woman’s needs and when the woman is ready to receive it

• Encourage social support from family and friends and include them in the plan of care (if the patient desires)

These suggestions may assist nurses providing care to women in day care surgery, diagnostic imaging, and/or the cancer clinic to develop a valuable "patient centered" understanding of the full impact of breast cancer on the woman and her family. The following section discusses implications for program planning and health care decision makers.

3.2 Implications for Program Planning

When a woman receives a diagnosis of breast cancer a complex process of coping with a potentially life-threatening illness and treatment begins. This population of women require comprehensive nursing interventions to improve their clinical outcomes through program planning and delivery of nursing care. Implications for program planning for the Day Surgery Unit include:

• Ensure that the unit is developed as an environment that supports patient centred care and a culture of patient safety

• Ensure that the unit maximizes the contributions of professional nursing staff as outlined in the previous section

• Shorten the waiting time whenever possible for tests, procedures, diagnosis and surgery
• Provide easy access for women to health care providers such as a phone number so they can contact a nurse if they have questions or want to review their plan of care, and provide evening and weekend clinic hours (Degrasse & Hugo, 1996)

• Provide opportunities for women to give feedback related to their experiences of the program and their breast journey as a form of program evaluation.

• When evaluating the program include qualitative feedback from women about their experiences and concerns in addition to satisfaction surveys and safety monitoring

• Support the introduction of an Advanced Practice Nurse (e.g. Clinical Nurse Specialist) to develop the nursing component of the program by providing individualized patient centered care throughout the women’s breast cancer journey

• Support the introduction of an Advanced Practice Nurse to provide leadership in the education of patients and families by developing, implementing and evaluating teaching programs and educational materials. An Advanced Practice Nurse also acts as a resource to other nurses and health care professionals.

A major challenge in program planning for women with breast cancer is to maintain evidence-informed practice that is also individualized to meet women’s needs. By understanding women’s needs, nurses can help women to be active participants in their care with the health care team. The next section discusses the potential contributions of an advanced practice nurse.
3.3 The Potential Contributions of an Advanced Practice Nurse

The suspicion of breast cancer initiates a complex process of patient reactions and coping strategies. The actual diagnosis of breast cancer may result in physical and psychological issues related to wide-ranging treatment options and care needs. Many centers providing the primary management of patients with breast cancer now have specifically designated nurses who provide practical advice and support (McArdle, George, & McArdle, 1996 & Maguire, Tait, Brooke, Thomas, & Sellwood, 1980).

This project has afforded me many opportunities to observe gaps in patient centered care where the competencies of an Advanced Practice Nurse could be utilized to improve patient care for this population of women. The introduction of the Clinical Nurse Specialist role, an Advanced Practice Nursing position that provides expert nursing care across the usual unit boundaries and leadership for practicing nurses and the health care team, could support women like Janine, Pat and Liu.

The following represents a comprehensive selection of practice areas where an Advanced Practice Nurse could contribute to the care of this selected population of women:

- Provide leadership for program and policy development for the new Day Surgery Unit
- Act as a clinical resource for physicians, nurses and other health care professionals and students by developing and/or providing formal and informal education programs
• Work collaboratively with the multi-disciplinary team to develop evidenced-informed patient care practice guidelines and decision support tools

• Provide comprehensive patient assessment and supportive nursing interventions for women and their family members

• Assist the women and their support network to understand the breast cancer journey including breast diagnostics, clinical findings at breast surgery and treatment options.

• Provide information and support to patients through their decision-making process regarding treatment and symptom management

• Advocate on behalf of the patient and family to support their choices and needs

• Develop or review educational materials so that a variety of resources/formats are available for women and families

• Provide education, mentorship and consultation for nurses and other members of the health care team

• Facilitate knowledge translation and evidenced informed nursing practice

• Provide leadership for the interdisciplinary team due to knowledge of health systems.
• Develop evaluation tools that consider patient safety, satisfaction and health outcomes including costs of care for both the health care system and the woman and her family.

• Provide leadership for knowledge translation as it relates to women’s breast cancer journey

According to Paalsson & Norberg (1995), the role of the nurse is pivotal for helping women during the time from suspicion of breast cancer until after treatment and during the recovery period. The most important tasks for nurses include listening, comforting, answering questions, clarifying misunderstandings, and identifying patient’s personal resources and coping strategies. The APN role will provide appropriate supportive care to women facing the diagnosis of breast cancer, as well as their families, and will help manage the wide range of emotions often described as a roller coaster ride. An APN in the Rapid Diagnosis Breast Health Clinic may be the only health professional to have prolonged contact with the woman throughout the disease trajectory, and has significant potential for role expansion while maintaining continuity of care.

The APN role can contribute to an improvement in health and well-being of women with breast cancer, both on physical and psycho-social levels (Paalsson & Norberg, 1995). The APN makes a significant contribution by providing supportive care to women undergoing diagnosis and treatment for a breast abnormality. APNs are indeed advocates, as the role assists patient and families in obtaining information to
meet their needs, clarify the information provided, and participate in the decision-making regarding care (DeGrasse & Hugo, 1996).

3.4 Questions for Further Research

It was learning about the needs of the woman and her family that led me to identify gaps in current nursing practice and areas that require further research. Based on the findings of my project, questions for future research related to the care of women with breast cancer who undergo day care surgery are:

- Understanding that women’s needs change along the continuum of care, how do we as nurses identify the learning needs of women with breast cancer at various points in their course of treatment?

- What impact do cultural differences have on women’s breast cancer experience, and how should these differences influence nursing care?

- How should nursing practice change when guided by an understanding of women’s needs for information about their breast cancer journey?

- Women experience enormous changes in their lives (physical, psychological, and family) after they receive a diagnosis of cancer. How can nurses provide effective and holistic care during the difficult times?

- How can nurses ensure continuity of care while the women with breast cancer transitions from one health care provider to another during the woman’s breast cancer journey?
These are examples of areas for future research and/or exploration in order to improve nursing care practices to women who have breast cancer and undergo day care surgery.

3.5 Summary

This paper has provided a detailed report of the project that focused on the experiences of women with breast cancer who undergo day care surgery. The overall purpose of this project was to carefully explore their breast cancer journeys and identify nursing care needs. The common thread throughout this project was a focus on women’s’ emotional and psychological experiences from finding a lump, to seeking medical attention, to diagnostic testing and then undergoing day care surgery.

The phases of the women’s breast cancer journeys have been studied using the lens of personal experience, a comprehensive literature review and the role of healthcare providers, particularly the APN role. Nurses need to be innovative in creating ways to assist women and promote their health and healing (Loftus & Weston, 2001).

The literature review and personal observations of three patients during their post operative journey provided the foundation for recommendations to improve nursing care for women during this experience as well as identify the implications for the planned SMH Rapid Diagnosis Breast Health Clinic. I have identified the potential contributions that an advanced practice nurse could make to improve patient centred care for this group of women and provide leadership for the new Breast Health Clinic. I have also identified research questions related to my project focus on women’s experiences with breast cancer. Through an in-depth exploration of both existing knowledge and new
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information related to this area of nursing clinical practice, this project has made a relevant contribution to the current body of nursing knowledge related to the care of women with breast cancer who undergo day care surgery.

As my project was coming to completion I wondered how I would know for sure that my contribution to the care of women with breast cancer made a difference in the life of at least one of these women. A few days later I was working in my office when I heard someone clear their throat. I looked up and in the doorway was Pat, standing with two ice cream cones in her hands with a big smile on her face. As our eyes met, we both broke out laughing. The significance of the ice cream was a reference to a conversation we had had prior to her surgery. At that time she was overwhelmed with the amount of information she had been given in a short period of time. She described the information that was given to her as “1000 ice cream cones on a hot summer day…it would have been nice to have one ice cream cone on another day.” As our laughter subsided Pat said to me “I am here to share one of those ice cream cones with you, I want to run something past you.” At that moment I realized I had made a difference in Pat’s life. During her journey I was able to build a trusting relationship with her and she knew she could come to me with her needs.


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