An Exploration of the Oncology Patient Navigator Role:

Perspectives of Younger Women with Breast Cancer

by

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Abstract

Background: One in nine Canadian women will be diagnosed with breast cancer within their lifetime. In Manitoba, an estimated 810 women will be diagnosed with breast cancer in 2011, with approximately 160 of those aged 20 to 50. Younger women diagnosed with breast cancer may have unique needs and challenges due to a variety of factors that include caring for younger children, career demands, or in some cases, family planning. Many women face a heightened sense of vulnerability after their diagnosis which challenges their physical, emotional, and spiritual self as they attempt to navigate through the complexities of the health care system. One approach to alleviate health care systemic challenges has been the establishment of patient navigation programs. To date, the role of the oncology patient navigator has not been examined from the perspectives of patients experiencing the oncology system of care without the services of an established patient navigator. Method: Consistent with the purpose of this study, an interpretive, descriptive qualitative research approach was utilized to describe the role of the oncology patient navigator from the perspectives of younger women aged 20-50 (n=12) diagnosed with an invasive breast cancer within the last three years. Face-to-face interviews were conducted and audio-taped to capture their descriptions of the oncology patient navigator based on their own experiences. Results: The role of the oncology patient navigator includes two facets - *personal attributes* and *essential processual needs* – for which the navigator could provide assistance. Conclusion: The results of this study depict the oncology patient navigator's vital attributes and processual facets based on the perspectives of younger women with breast cancer. This study can be utilized for the purposes of tailoring or expanding current roles in oncology or perhaps cultivating the development of new navigational programs to address the needs of younger women with breast cancer.

"The whole world stopped because I could not comprehend another thing after that. All I heard was cancer. First thing you think of is death…"

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Dedication

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CHAPTER 1: STATEMENT OF THE PROBLEM

A diagnosis of breast cancer results in a multifaceted illness trajectory for both patients and their families as they experience this life changing event. The Canadian Cancer Society (CCS) estimates that 1 in 9 Canadian women will be diagnosed with breast cancer in their lifetime, and 1 in 29 will die of the disease (CCS, 2011). In Manitoba, 810 women were diagnosed in 2009 with approximately 160 of the women being between the ages of 20 and 50 (C. Clague, CancerCare Manitoba Epidemiology, personal communication, June 2011). The complexities of cancer treatment and the increased supportive care needs for these patients have been the impetus for the development of streamlined systems care delivery (Canadian Partnership Against Cancer, 2009). Notwithstanding the efforts of the Canadian health care system, significant gaps continue to challenge patients and their families as they navigate their way through the cancer care labyrinth.

The period following a breast cancer diagnosis is fraught with a plethora of challenges for patients as they often feel an increased sense of vulnerability and uncertainty (Doll et al., 2003; Melinyshyn & Wintonic, 2006). Person-centred care has assisted in decreasing anxiety and vulnerability in the oncology patient population. This approach includes the patient’s point of view and their unique needs which are imbedded in the care plan (Fitch, 2008; Thomsen, Pedersen, Johansen, Jensen, & Zachariae, 2007). A study by Hack, Degner and Parker (2005) illustrated a significant increase in women’s desires to participate in their treatment plans, emphasizing the importance of educating and assisting patients during the treatment decision making phase of their illness trajectory. As well, research has indicated that women rank knowledge of how and where to get information as one of their highest needs upon receiving a diagnosis of breast cancer (Gould, Grassau, Manthorne, Gray & Fitch, 2006; Melinyshyn &

Wintonic, 2006). Thus, education and information provision are vital for women with breast cancer, as they attempt to participant in their treatment decision making process.

The cancer care treatment trajectory is riddled with a myriad of complexities for patients living in both urban and rural environments. However, rural areas often pose additional obstacles and challenges for women diagnosed with breast cancer due to the travel associated with care and the lack of facilities offering supportive care services. Rural women with breast cancer, often undergo more invasive surgical approaches for their breast cancer due to limited treatment resources. For example, research has illustrated that women living in rural areas are less apt to choose breast conserving treatments than those living in urban centers (Beaulieu, Massey, Tucker, Schoenberg, & Ross, 2003; Canadian Breast Cancer Network, 2001; Meden, John-Larkin, Hermes, & Sommerchield, 2002). This is often the case as a mastectomy procedure may eliminate the need for adjuvant radiation, thus less travel required for treatment. Despite evidence indicating that a lumpectomy followed by radiation remains as effective as a mastectomy, many rural women with breast cancer often undergo the latter procedure.

As the numbers of support groups, treatment options and informational resources are limited and sometimes more difficult to access, rural women with breast cancer face immediate disadvantages to those living in urban centers. This may have a profound effect on patient anxiety and feelings of vulnerability as they attempt to understand their upcoming future and treatment plans. Research has indicated that a lack of coordination of care results in unnecessary delays of treatment (Ell, Vourlekis, Lee & Xie, 2007). This reported lack of coordination and communication has also been shown to exacerbate patient anxiety and uncertainty (Thorne, Bultz & Bailey, 2005). Unfortunately, navigating the health care system for many patients and families, becomes a labor intensive effort.

One strategy aimed at enhancing coordination of care while reducing systemic obstacles is the implementation of cancer patient navigation programs (Doll et al., 2003; Freeman, Muth & Kerner,1995; Ell et al. 2007; Melinyshyn & Wintonic, 2004; Psooy, Schreuer, Borgaonkar, & Caines, 2004). The role of the patient navigator remains as diverse as the settings in which it has been implemented (Pedersen & Hack, 2010). The reviewed literature illustrates that the roles and responsibilities of oncology patient navigators are essentially determined by the facility or domain in which they serve.

Patient navigation programs have also been developed to facilitate supportive care for individuals requiring ongoing information, education, and resource connections. Patient navigation is believed to be an approach towards comprehensive care provision by striving to meet the multifaceted needs of patients facing the complexities of the breast cancer treatment trajectory. To date, the role of the oncology patient navigator has not been empirically examined from the perspectives of younger women diagnosed with breast cancer who have not received the support of a patient navigator. With this in mind, this study will assist in addressing this gap that remains in the scientific literature.

Purpose of the Study

The purpose of this interpretive, descriptive qualitative research project was to explore and articulate the role of the oncology patient navigator utilizing the perspectives of younger women with breast cancer. The emotional, informational, financial and social needs were gleaned through face to face interviews which assisted to inform the role of the oncology patient navigator. The central questions guiding this study included:

1. What are the perceived unmet needs of younger women going through treatment for breast cancer?

2. How might a patient navigator meet these needs?

3. What does the role of the oncology patient navigator look like, from the perspectives of younger women with breast cancer?

In order to answer these questions, a prudently designed list of probing questions were imbedded in the interview guide. The information surrounding the role of the oncology patient navigator was carefully gathered from the experiences and needs of the younger women with breast cancer thus, the emic, or insider's perspective, was used to help delineate the role.

Assumptions Underlying the Study

The following assumptions underlie this study:

1. Despite Manitoba's development of resources for patients with breast cancer, needs remain unmet.

2. Younger women with breast cancer experience delays associated with their diagnosis, treatment and resource connections.

3. Younger women with breast cancer are able to express their unmet needs.

Significance of the Study

The impact of a breast cancer diagnosis and the burdens associated with treatment are overwhelming for many patients. This study will provide pertinent and empirically based insight into the role of the oncology patient navigator from the perspectives of younger women with breast cancer. This research will also capture the patient's perspective on the gaps that remain in cancer care delivery thus providing insight for care managers and program coordinators to address these facets of care. As research has indicated, many centers have experienced the benefits of navigation programs which have ultimately assisted patients and their families through their experience with cancer (Ell et al., 2007; Psooy et al., 2007; Melinshyn & Wintonic, 2006). This research will contribute to further studies attempting to develop and implement patient navigation programs not only in breast cancer, but also other cancers and chronic diseases.

Summary

This chapter described the statement of the problem and delineated the purpose of this research study. The assumptions underlying this study were also presented along with the study's significance. The following chapter will discuss a review of the empirical literature related to the study.

CHAPTER 2: REVIEW OF THE LITERATURE

A review of current literature spanning from the 1990s, when the concept of navigation was developed, to the present, revealed that navigation is a fairly new concept in Canada and many provinces remain in the initial stages of implementing services. The role of the patient navigator is fairly diverse and context specific. The literature review included PubMed, MEDLINE, CINAHL, Google Scholar, and Google search engine. The following literature review is organized and critically reviewed according to these categories: the impact of breast cancer on young women, rural women with breast cancer, anxiety and information needs for women with breast cancer, the definition of an oncology patient navigator and patient navigation services and programs.

The Impact of Breast Cancer on Younger Women

Young women with breast cancer face a unique set of challenges including: the potential loss of fertility, early menopause (Adams et al., 2011; Coyne & Borbasi, 2006; Gould et al., 2006; Thewes, Butow, Girgis, & Pendlebury, 2004), disruptions to their careers or education (Gould et al., 2006; Mosher & Danoff-Burg, 2005) and in many cases, concerns for their young children (Avis, Crawford, & Manuel, 2004; CBCN, 2001; Gould et al., 2006). Young women with breast cancer may also feel isolated among the broader cancer population because of their stage of life and younger age (Gould et al., 2006). In response to these findings, support groups designed specifically for younger women with breast cancer have been established in numerous Canadian cities.

Many studies have shown that younger women, compared to older women, have a more difficult time adjusting to a diagnosis of breast cancer (Bloom & Kessler, 1994; Dunn & Steginga, 2000; Ganz, Greendale, Petersen, Khan & Bower, 2003; Mor, Malin & Allen, 1994) and tend to have higher anxiety throughout their entire disease trajectory (Wenzel et al., 1999). Some studies have even shown that younger women diagnosed with breast cancer, have a higher incidence of cancer related posttraumatic stress disorder symptoms (Cordova, Studts, Hann, Jacobsen, & Andrykowski, 2000; Koopman et al., 2002). Several causes of increased anxiety in younger women with breast cancer include the potential for infertility after treatment, sexual functioning (Avis et al., 2004), motherhood demands, and role transitions (Coyne & Borbasi, 2006). Current treatments for breast cancer may cause early-onset menopause potentially impacting family planning for younger women.

Thewes et al. (2004) qualitatively explored the needs of women who underwent treatment for breast cancer and found that the younger women in their study desired specific information and support surrounding (treatment induced) menopausal symptoms and contraception. This study also found that the younger women had increased difficulty in coping with changes associated with sexuality (Thewes et al., 2004). Parle, Gallagher, Gray, Aker & Liebert (2001) found that factors such as: being under the age of fifty, having children under the age of twenty-one, having low social support, living alone and being single, contributed to an increased risk of psychosocial morbidities. Further, a meta-ethnography conducted by Adams et al. (2011) reviewed 17 studies related to women under the age of 45 diagnosed with breast cancer. Adams et al. found congruence with the previously mentioned young women's studies but also reported that younger women may face additional obstacles due to their relationship status and/or social support network. For example, they state, “young women are more likely to be in new relationships or no relationships than older women and may therefore be more isolated when diagnosed with breast cancer” (Adams et al., 2011, p. 4). As well, they found that some studies revealed the possibility of a more fluid and “less established” social support network in younger women. A lack of social support may result in increased distress and anxiety for younger women enduring treatment for breast cancer.

The above studies delineated several of the devastating effects a diagnosis of breast cancer has on younger women. Considering these aforementioned studies, age may be best viewed as a significant risk factor for anxiety and distress for younger women diagnosed with breast cancer.

Rural Women with Breast Cancer

A brief review of the literature related to rural women with breast cancer, was performed due to the study criteria including the perspectives of both urban and rural patients with breast cancer living in the province of Manitoba. The review revealed unique needs and challenges for rural patients due to the limited services and resources. Research, specific to breast cancer, has demonstrated that rural women experience increased barriers to care compared to women in urban centres (CBCN, 2001; Hampton, 2008; Mitchell et al., 2006). Travelling long distances for treatment and care adds physical, emotional and financial burdens associated with treatment for patients and families who are already experiencing a stressful, life-altering event (CBCN, 2001; Eley et al., 2008; Mitchell et al., 2006). Supportive services including professionally-led support groups and accessibility of up-to-date information are also limited in the rural community environment (Mitchell et al., 2006; Eley et al., 2008).

A large Australian study (n=899) found that rural women less likely to receive adjuvant hormone therapy and less liable to have their treatments managed by a “high caseload surgeon”. A high caseload surgeon was defined as having one new patient with breast cancer every 2-3 weeks which allowed the surgeon to maintain a high skill level (Mitchell et al., 2006). Unfortunately, the rural women in this study experienced higher mortality rates compared to those living in urban centres (Mitchell et al., 2006). The difference in survival rates was reportedly related to “variations in disease management” such as, the inconsistent or decreased use of adjuvant hormonal therapy in the rural patient population. The study reported, “Of breast cancers suitable to be treated with hormonal therapy, therapy was given to significantly more to urban patients than rural” (p. 775) despite their effectiveness in reducing breast cancer recurrence.

Research has also reported on the increased incidence of rural women compared to urban women undergoing mastectomy procedures rather than breast conserving surgeries (CBCN, 2001; Eley et al., 2008; Celaya, Rees, Gibson, Riddle & Greenberg, 2006; Mitchell et al., 2006). Notwithstanding the established evidence that breast conserving procedures followed by radiation therapy yield equivalent survival rates (Fisher et al., 2002; Veronesi et al., 2002), mastectomies are often the chosen method of treatment for rural women (CBCN, 2001; Jacobs, Kelley, Rosson, Detrani & Chang, 2008; Mitchell et al., 2006). It has been reported that this may be due to the travel complexities associated with radiation therapy (Celaya et al., 2006; Mitchell et al., 2006) as treatments are often five times per week for approximately four to six weeks. Further, Celaya et al. (2006) found that women who opted for breast conserving surgeries but required radiation follow-up were less likely to undergo the adjuvant radiation if they lived twenty miles or more from the treatment facility. This translates to an increased risk for recurrence and lower survival rates for these women (Fisher et al., 2002).

Another study identified a discrepancy between screening rates for rural women compared to their urban counterparts (Lane & Martin, 2005). The study reported that rural women are screened less than urban women due to the lack of knowledge regarding screening requirements and access to screening resources. On the contrary, the current breast screening rates in Manitoba are analogous between the rural and urban population due to the expansion efforts of the Manitoba Breast Screening Program (K. Watters, personal communication, June 27, 2011).

Some of the above studies highlight significant differences in both treatment recommendations and surgical procedures between the urban and rural patient populations which may negatively influence health outcomes. Additionally, the emotional side of breast cancer for both rural and urban women can often become as debilitating as the physical burdens associated treatment.

Anxiety and Information Needs of Women with Breast Cancer

Approximately one third of women who undergo treatment for breast cancer develop psychological morbidity (American Cancer Society, 2008; Zabora, Britzenhofe-Szoc, Curbow, Hooker, & Piantadosi, 2001). Research has demonstrated that anxiety and emotional distress persist throughout the disease continuum, from the moment cancer is suspected, to diagnosis, treatment and beyond (Bultz & Holland, 2006; Carlson & Bultz, 2003). For example, the period following a diagnosis of breast cancer is often filled with periods of anxiety about upcoming treatment plans and disease prognosis (Knobf, 2007; Wintonic & Melinshyn, 2006). Patients' information requirements fluctuate as they progress through their journey of breast cancer thus accessibility of accurate and up-to-date information is pivotal for patients as they attempt to understand their diagnosis and treatment (Thomsen et al., 2007). Common themes from research suggest that patients are concerned about the information surrounding their diagnosis and treatment (Degner et al., 1997), and their ability to comprehend and retain the information provided to them (Griggs, et al., 2007; Melinshyn & Wintonic, 2006). As stated by T. Hack, "The challenge for the physician is to determine the appropriate type and amount of information to give to patients, and the challenge for patients is to know what questions to ask" (personal communication, November, 2008). Many situations arise where the information provided by doctors and nurses does not always reflect the information that patients retain or understand (Hack et al., 2005; Parker, Davison, Tishelman, Brundage & SCRN Communication Team, 2005). This research illustrates the profound necessity to provide ongoing education and repetition of information, while simultaneously assessing the patient's understanding.

Research has also reported that women have difficulties hearing and processing *any* information immediately after they have been diagnosed with breast cancer (Parker et al., 2005, Palsson & Norberg, 1995). Thomsen et al. (2007) stress the importance of sustained communication throughout the journey of breast cancer. Some women in their study felt that having the same person assigned to them through part of the treatment cultivated a personal relationship which was a positive influence within their treatment trajectory. A common theme for the women was the need for clear, concise information and having their emotional needs met. This exemplifies the complexities and uniqueness of individual needs as some patients preferred a well-defined, pre-planned approach, while others preferred to be consulted when planning their treatment care plan (Degner et al., 1997; Thomsen et al., 2007).

A study by Griggs et al. (2007) compared vitality, mental health and satisfaction with information patients had received during their breast cancer treatment trajectory. They found the patients' level of satisfaction with information during their diagnosis and treatment was positively associated with general health. Women who stated they were *more* satisfied with the information concerning their treatment had significantly higher vitality and mental health scores.

Research also illustrates the effects of anxiety on information retention as women who experience moderate levels of anxiety have difficulty focusing (Luker, Beaver, Leinster, &

Glynn Owens, 1996; Stephenson, 2002). This demonstrates the challenges of teaching information to patients without first assessing their levels of anxiety. Information related to diagnosis, treatment and resources should be prioritized and readiness for learning assessments need to be performed. Stephenson (2002) suggests relaying information to patients through various venues including videos, face-to-face education, booklets and internet sources. Nurses need to assess whether information should be titrated over time or given in larger quantities depending on their patient's readiness to learn. With this in mind, healthcare providers should also be cognizant of their patients' needs changing throughout their disease treatment trajectory.

Satisfaction with information has also been demonstrated to have positive outcomes for patients as it is associated with lower perceived levels of distress and uncertainty (Rehnberg, Absetz, & Aro, 2001). Rehnberg et al. (2001) evaluated patient satisfaction with the information they received. Patients rated the provision of information as their third most supportive factor out of 67 other alternatives. Patients felt that "sufficient information" and sharing the "matter of fact information at every stage" were most helpful.

Luker et al. (1996) reported that many women feel uncomfortable asking professionals for information. Women reported feeling that their problems were insignificant and stated that if a professional had called them, via telephone, they would have felt better voicing their concerns. This study noted patients' heightened state of anxiety during various stages of the illness trajectory, emphasizing that information provision should be goal directed and appropriate for the current stage of the illness trajectory. For example, women coming in for a mastectomy may be concentrating on their survival. Therefore, discussing the potential impact of their surgery on sexual attractiveness would not be appropriate at this stage. Further, a study conducted by Beaver et al. (2009) illustrated the positive impact of a nurse-led telephone follow-up intervention with patients who had completed treatment for breast cancer. The study found that women in the telephone group reported greater levels of satisfaction than women who travelled to clinics for their follow-up examinations.

O'Leary, Estabrooks, Olson & Cumming (2007) performed a systematic review of literature concerning information needs around the time of a breast cancer diagnosis. Their results showed that women are in a heightened state of anxiety and information needs are high. Providing information concerning the patients' prognosis and chance for a cure are important for these women. This information serves as a gauge for patients in determining how threatening their cancer might be. Research has reported that information and supportive care needs may change as women progress through their breast cancer trajectory thus influencing their coping and anxiety levels (Raupach & Hiller, 2002). With this knowledge, programs such as patient navigation have been developed in an effort to reduce patient anxiety by increasing supportive care throughout the breast cancer disease trajectory (Melinyshyn & Wintonic, 2006; Schwaderer & Itano, 2007).

The Definition of an Oncology Patient Navigator

Patient navigation was originally coined in 1990 by Dr. Harold P. Freeman, a distinguished surgical oncologist and former president of the American Cancer Society (Freeman et al., 1995). Dr. Freeman and colleagues implemented the first patient navigation program in Harlem Hospital, New York, to serve marginalized communities. The intent of the program was to expedite diagnostic and treatment services while facilitating access to care for individuals with abnormal breast screening results. The program's success served as the impetus for further utilization and investigation into the development and understanding of the patient navigator role (Ferrante, Chen & Kim, 2007; Schwaderer & Itano, 2007; Wells et al., 2008).

The writer formally investigated the concept of an oncology patient navigator and completed a concept analysis (Pedersen & Hack, 2010). For the purposes of this proposal, a summary of the findings are presented. Pedersen and Hack (2010) found that an oncology patient navigator is defined as, "(1) a trained individual who facilitates timely access to appropriate health care and resources for patients and their families, (2) a skilled communicator, who provides holistic care, empowering patients with education and knowledge about their illness, and (3) an individual who is knowledgeable of the cancer system" (p.59). It is important to mention that the concept of a patient navigator frequently varies within the reviewed literature thus potentially complicating an already complex role. Breast cancer nurse navigators have been defined as nurses who initiate contact with newly diagnosed patients to offer support, education, and information concerning their diagnosis (Doll et al., 2003; Ell et al., 2007; Psooy et al., 2004). Other definitions of patient navigators extend the role right through to the end of treatment (Carroll et al., 2010; Corporate Research Associates, 2004; Fillion et al., 2006). A study conducted by Carroll et al. (2010) utilized lay patient navigators to assist patients through the complexities of either breast or colorectal cancer care and treatment. The navigators provided an assessment of barriers to appropriate health care for their patients. The aim of the study was to influence patient's perspectives on the quality of the health care they were receiving. They found that patients valued the informational support from the navigators which included: arranging follow-up tests, addressing financial concerns, and coordinating insurances. The navigated group of patients in this study valued the services provided by the navigators.

Patient Navigation Services and Programs

Navigation programs have evolved over the years in a variety of domains. The goals across Canada include *timely* access to care (Melinyshyn & Wintonic, 2006; Psooy et al., 2004), provision of information and education (Melinyshyn & Wintonic, 2006), co-ordination of care (Fillion et al., 2006) and providing links to community resources (Melinshyn & Wintonic, 2006; BC Cancer Agency, 2004; Corporate Research Associates, 2004). Patient navigation seems to be a diverse area with much concentrated interest and various definitions of the role seem to exist. This could, in part, explain the diversity of the various navigation programs.

Psooy et al. (2004) reported on a retrospective study of 536 women who underwent a breast core biopsy comparing 6 month periods in 1999 and 2000, to determine the effects of patient navigation, age, and biopsy result on the wait time for biopsy after diagnostic imaging. The analysis confirmed a statistically significant decrease in wait time for patients assigned to the navigation group. This study facilitated the need for further investigation into the potential influences of patient navigation in the province of Nova Scotia.

Koh, Nelson and Cook (2011) evaluated their breast cancer patient navigation program that had previously been established in their facility. The care goals for their program included timely access, removing barriers and improving patient satisfaction. A comparison between the non-navigated and navigated group revealed that patient satisfaction was highest in the latter group. This study also reported a decrease in wait times to appropriate care for their navigated patients. Several reports have illustrated significant benefits for both patients and health care clinicians involved in navigation programs (Corporate Research Associates, 2004; Doll et al., 2003; Ell et al., 2007; Melinshyn & Wintonic, 2006; Psooy et al., 2004). Corporate Research Associates, Inc (2004) reported on the efficacy of Nova Scotia's patient navigation program. The research consisted of both a qualitative and quantitative analysis evaluating the effectiveness of the structures, communication plans, referral processes, and reporting mechanisms. Their data were collected through focus groups, one-on-one interviews with patients, patient surveys and a review of the patient navigation database. Results from the analysis concluded that the program produced significant improvements in overall care for patients and families throughout the cancer illness trajectory. Narratives from patients indicated a notable decrease in feelings of anxiety, stress and fear with the help of the patient navigator. The results from the patient surveys were as follows: 79% of respondents stated they felt less anxious and 85% of respondents felt the information from the navigator was explained and understood comprehensively. Notwithstanding these positive results, the report also discussed weaknesses within the program including the workload of the patient navigator. As patient navigator programs gain momentum, the navigator's demands for time have become an additional issue.

Some navigation programs have queried the necessity of having a nurse assume the role of patient navigator. Fillion et al. (2006) found that the comprehensive triaging of patient needs and ongoing complexities of oncology care stress the requirement for navigators to be not only nurses, but nurses who have specialized in oncology. Melinshyn and Wintonic (2006) believe that nurse navigators have the knowledge to effectively provide comprehensive educational support to patients further emphasizing the requirement for nurses to assume the navigator role. The Victoria Breast Health Centre in British Columbia has two breast health patient navigators who, "assist patients by answering questions, preparing patients for treatment visits with specialists, informing people of community supports, helping people navigate the cancer care system, and providing emotional support" (Vancouver Island Health Authority, 2011). One of the nurse navigators described their program as a support to patients from the point of abnormal finding to post-operative follow-up (S. Bond, personal communication, June 22, 2011). Thus, the nurses provide education and emotional support throughout the treatment decision making process until the patient transitions to their medical oncologist for consultation. Patients are welcome to continue receiving support from the nurses during this time period, but the nurses no longer provide telephone follow-up. Most noteworthy is the timing of the follow-up provided by the nurses at Victoria Breast Health. They contact patient by telephone during the pre-operative or post-operative stage if the patient has not initiated contact before that time. This model of navigation addresses the diagnostic and treatment decision making phase which is well-known to be one of the most stressful times within the breast cancer illness trajectory.

Due to the diverse nature of the patient navigator role, it is essential to understand both the complexities of care and unmet needs perceived by younger women before implementing a patient navigator role aimed at ameliorating care for this specific population.

Limitations in the Literature

The concept of patient navigation has received a groundswell of activity over the last decade. Despite this attention, future investigation of the protocols for establishing a patient navigator program and defining the navigator role are required. Another domain requiring further research is measuring the efficacy of patient navigation and determining the most cost effective approaches to these programs. Further research concerning the patient's perspective on the patient navigator role, is required to glean insight into how a patient navigation program might meet the unique needs of certain patient populations.

Significant gaps remain in the literature considering the vast array of domains that have the potential to be influenced by navigation programs. Instruments designed to measure the success of navigation programs also require further investigation.

Notwithstanding the strides Manitoba has made in their various efforts to meet the both the psychosocial and physical needs of patients going through treatment for breast cancer, a gap remains in the literature concerning Manitoba's concept of navigation as it is fairly new to the province. Patient navigators have not been implemented into the Manitoba cancer care delivery system thus far. The effect of implementing a patient navigator for breast cancer patients in Manitoba is unknown. As the research review has revealed positive impacts of these programs, the insight gained from this study will help facilitate the development of a patient navigator role for younger patients with breast cancer living in Manitoba.

Summary

This chapter provided an overview of the empirical literature pertaining to this study which included: younger women with breast cancer, rural women with breast cancer, anxiety and information needs of women with breast cancer, the current definition of an oncology patient navigator and existing patient navigation services and programs. Limitations in the literature pertaining to this study were also presented. The following chapter will discuss the methods and procedures utilized to conduct this study.

CHAPTER THREE: METHODS AND PROCEDURES

This qualitative study utilized an interpretive, descriptive methodology for addressing the purpose of exploring and describing the role of the oncology patient navigator from the perspectives of younger women with breast cancer. Thorne describes interpretive description as a smaller scale inquiry into a clinical phenomenon of interest to nursing for the purpose of capturing themes from subjective perceptions (Thorne, 2008). Interpretive description allows researchers to produce data capable of informing clinical understanding related to human health and illness experiences. Thorne (2008) emphasizes that interpretive description methodology is ideal for assisting with the development of nursing knowledge. By utilizing interpretive description, this study was able to gather the experiences of twelve younger women with breast cancer and attempt to introduce their perspectives related to the patient navigator role based on the challenges or obstacles they had previously delineated. Therefore, this method was appropriate for exploring and informing the role of the oncology patient navigator.

The Supportive Care Framework conceived by Fitch (2008) provided the sensitizing concepts utilized to guide the researcher in this study. Some of the sensitizing concepts within the framework include appraisal, coping, and adaptation with regard to how human beings both experience and cope with their cancer (Fitch, Porter & Page, 2008). The Supportive Care Framework identifies the constructs of human needs, coping and adaptation and describes how these “provide a basis for conceptualizing how human beings experience and deal with cancer” (Fitch et al., 2008, p. 12).

Fitch et al. (2008) describe human needs with relation to the context of cancer and elucidates the loss of routine that is often experienced as patients endure their cancer treatments. They state, “A situation may arise that creates new demands, and anxieties can begin to emerge;

feelings of vulnerability can unfold together with a sense of loss of control over a situation and uncertainty about what to do" (p. 12). Supportive care is defined as, "the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, psychological, informational, spiritual and practical needs during the diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliative care and bereavement" (Fitch et al., 2008, p.11). Supportive care must be provided with consideration given to the individual's needs and goals, keeping in mind, their unique frame of reference. The purpose of this research was to explore and articulate the role of the oncology patient navigator based on the needs of younger women with breast cancer, thus this framework was well suited in providing the sensitizing concepts for this study.

Participants

In interpretive description, individuals living the experience are sampled because they are considered to be the best source of knowledge surrounding the phenomenon under study (Thorne, 2008). The inclusion criteria for all participants were as follows:

1.) Women aged 20-50 with a diagnosis of invasive breast cancer. Women aged 51-69 are considered "older" according to the province of Manitoba's Breast Screening Program. Women diagnosed with ductal carcinoma in situ (DCIS) were not approached to participate in the study. DCIS does not require chemotherapy and does not usually involve radiation treatments consequently resulting in a less complex treatment trajectory.
2.) All participants were diagnosed or treated for breast cancer within the last three years.
3.) All participants resided in the province of Manitoba.
4.) All participants were recommended to chemotherapy or radiation treatments.

5.) All participants were able to understand and speak English and were deemed competent by the researcher to provide informed consent.

In order to capture the valuable experiences and perspectives from rural patients, attempts were made to include the recruitment of patients living outside the city of Winnipeg.

Data Collection

Data collection was performed by the researcher and commenced after approval was received by the Research Resource Ethics Committee (RRIC) of CancerCare Manitoba and the Education Nursing Research Ethics Board (ENREB) of the University of Manitoba. The study was advertised in various departments within CancerCare Manitoba (APPENDIX B) including the chemotherapy areas, the Breast Cancer Centre of Hope and the psychosocial oncology departments. The Community Cancer Programs Network (CCPN), who provides oncology guidance to sixteen rural community cancer centres within the province of Manitoba, provided further assistance in advertising the study. Nurses and social workers, within the previously mentioned departments, were given a script (APPENDIX E) and asked to introduce the study to eligible participants. The participants contacted the researcher via telephone or email to inquire about the study. The researcher was then able to both qualify the participant and provide a detailed description surrounding the purpose of the study and the length of the interviews. For those who agreed to participate, an interview was then scheduled around a mutually convenient time and place for both the participant and the researcher. Most interviews were conducted face-to-face, within the participants' homes. One interview was conducted via telephone and two took place within the researcher's home, as the latter was preferred by the two participants. All interviews commenced once a thorough explanation of the study was conducted, and a review and signing of the consent form were completed. A short demographics form was also completed by the participants during this time. The researcher answered all questions related to the study before the interviews commenced. Interviews ranged between 45 minutes and 2 hours in length resulting in detailed, in-depth transcripts. All participants granted permission to have the interviews audio-taped and confidentiality and privacy were maintained.

The interviews commenced with open-ended questions directed toward the patient's breast cancer experience (APPENDIX A). Other questions concentrated on the challenges or obstacles patients faced during their cancer care trajectory. Direct questions were also asked concerning information availability, resources, and the concept of the patient navigator. The discussion surrounding the patient navigator was utilized to drive the midpoint of the interview. Questions such as, "Have you heard of patient navigation?" and "Would you use the services of a navigator?" were utilized to open the discussion concerning the patient navigator role. Closing questions included a participant focused inquiry such as, "What advice would you give to another woman diagnosed with breast cancer?" and "Is there anything else you would like to tell me about your experience?" Field notes were made after each interview for two purposes. First, the researcher recorded observations concerning the setting and the observed non-verbal behaviours displayed by the participants. The second purpose for the field notes was for reflexivity which acknowledges the researcher's personal biases and past experiences that emerged while conducting the study. Further to this, regular discussions regarding the researcher's feelings and thoughts about the interviews were conducted between the researcher and her thesis advisor.

Data Analysis

The aim of the data analysis was to gain an understanding of the experiences of younger women living in Manitoba who had been diagnosed with breast cancer, and explore their perspectives on the role of the oncology patient navigator. The interpretive description was created by reviewing the transcripts thoroughly and repeatedly over time. First, the audio-taped data were reviewed immediately following all interviews. A transcriptionist was hired to transcribe all data following each interview. The researcher then reviewed the transcribed data compared to the audio tapes to ensure accuracy. The transcripts were reviewed on an ongoing basis in an effort to establish emerging themes. Data analysis occurred concurrently with data collection and a constant comparative method of data analysis was employed (Thorne, 2008). Interpretive description requires that an ongoing review of the data be employed to confirm, explore and expand on concepts that begin to formulate immediately as the researcher enters the collection process (Thorne, 2008). Tenets from grounded theory such as constant comparative techniques were utilized in an attempt to saturate the categories identified by the researcher (Glaser & Strauss, 1967). Ongoing coding and studying of the data assisted in providing meaning to all units of data, which was critical to the development of the emerging categories and themes. Data were broken down and inductively coded into four categories which assisted in establishing the organization of the data. The researcher then spent further time reading the interviews and immersing herself into the data while keeping the four categories in mind. The data was then coded and integrated into the four categories providing a description of the participant’s experiences and perspectives.

Further analysis of the data was implemented once data saturation was reached which included, repeated reading of the interview transcripts, conducting an in-depth analysis of the categories and their interpretations, as well as a comparison of the identified themes to the relevant literature. In keeping with interpretive description’s processes of intellectual inquiry, questions about the data such as, “Why was this said here?” And “What does this mean?” were utilized to guide the analysis into the four categories (Thorne, Reimer-Kirkham, & O'Flynn-Magee, 2004).

One of the steps in the qualitative data analysis process involves member checking which calls on the participants to review and concur with the interpretations and initial descriptions that the researcher constructs (Thorne, 2008). This step of the analysis was not performed in this study; however, the researcher frequently asked for clarification during the interview process, took additional steps to reiterate the information exchanged, and audio-recorded all interviews to ensure information was not missed or misunderstood. The study findings were also reviewed by an expert in the field of patient navigation who stated that the findings were congruent with other studies in the field. This was discussed between the researcher and one of her committee members and was determined appropriate for this study.

Ethical Considerations

This proposal was submitted and received approval from the Education Nursing Research Ethics Board (ENREB) of the University of Manitoba and the Research Resource Ethics Committee (RRIC) of CancerCare Manitoba.

The main ethical considerations were to keep participants free from harm and/or discomfort, allow for self-determination, informed consent, and confidentiality/anonymity as outlined in the Belmont Report (Polit & Beck, 2008). The researcher obtained permission to refer patients to psychosocial oncology services or available support services within the community if participants appeared to be struggling with emotional distress. In one case, the researcher referred a patient to Patient and Family Support Services at CancerCare Manitoba and provided the individual with the telephone number. The participant stated that she was happy to have received this information.

Prior to the interviews, the researcher provided potential participants with a detailed explanation of the study's purpose and answered all questions related to the study. Consent forms emphasized that all participants have the right to participate or withdraw from the study at any time illustrating the concept of self-determination. A copy of the signed consent form was provided to each participant. The participants were also given the option to receive a summary of the study findings upon completion of the research.

All transcribed data were stored in a locked filing cabinet in the researcher's home. All recorded interviews and conversations between the researcher and participant, were kept in confidence, according to the ethics outlined by the Canadian Nurses Association (Canadian Nurses Association, 2002). Transcripts, as previously stated, were reviewed by the researcher and her thesis advisor only. The transcribed interviews were saved on a memory stick, which was then given to the researcher and saved on the researcher's computer hard drive. The data on the memory stick was immediately deleted after being saved on the researcher's computer. No identifying information appeared on any of the data collected for this research study. Field notes and demographic data were identified by code numbers assigned to each participant. This data were also kept in the locked filing cabinet. An aggregate approach was employed to present the study findings which maintained participant anonymity.

Rigor

The concept of rigor in qualitative research refers to the assurance of the validity and reliability of the study findings (Morse & Field, 1995). Credibility refers to the accuracy of the descriptions or interpretations of the data (Sandelowski, 1986). Further, Lincoln and Guba (1985) emphasize that credibility is one of the most important aspects of trustworthiness. In addition, Creswell (2007) states that researchers may validate the accuracy of their findings by employing the use of "peer or external auditors of the accounts" (p. 46). In this present study, the researcher validated the study findings by utilizing a variety of means to ensure accuracy. One of Canada's well known patient navigation development managers reviewed the findings of this study and commented on their congruency with previous studies. Data were collected over a period of ten months and the researcher simultaneously reviewed the transcripts to ensure a deeper understanding of the experiences of the participants. The data analysis and coding were discussed on an ongoing basis with the researcher's thesis advisor ensuring the validity of the emerging framework and corresponding themes. The main categories, themes and sub-themes were submitted to an additional committee member for further face validity. According to Patton (2002), the credibility of the researcher conducting the qualitative research is important and adds an essential element to the study's rigor. Despite being a neophyte in the field of research, the researcher has studied patient navigation over the past four years and published two peer-reviewed articles on patient navigation. The researcher also worked as a breast cancer nurse educator who assisted patients and families along the breast cancer disease continuum.

Consistency or auditability refers to another aspect of ensuring rigor. Sandelowski (1986) states that studies are auditable when the study can be replicated by another researcher who "can clearly follow the decision trail used by the investigator in the study" (p.33). The steps utilized to execute this study, including the sampling criteria, the rationale for the interview guide, the interview setting and the data collection process, have been clearly outlined. In addition, the steps involved in the data analysis process were illustrated for further clarification and ease of replication.

Additional criteria used to ensure rigor include the concept of transferability identified by Lincoln and Guba (1985). Transferability refers to the extent to which the study findings can apply or transfer to other contexts or settings. Due to the small sample (n=12) utilized in this study and its exploratory nature, the results provide a general description of the role of the oncology patient navigator from the perspectives of younger women with breast cancer however, further studies may provide additional insights into this role.

The concept of dependability was also utilized to ensure rigor within this research study. Dependability refers to how reliable the study results are and should be incorporated into the measures of rigor. One strategy targeted towards ensuring dependability is referred to as triangulation. Patton (2002) refers to triangulation as a means to strengthen a study by using several kinds of methods or data. Triangulation was used within the context of data collection which means the researcher considered data from the interviews, the reflexive journal notes, and the scientific literature.

Summary

This chapter described the methods and procedures employed for this study. A description of the methodology, sensitizing concepts from the Supportive Care Framework and the procedures for recruitment were presented. This chapter also included a detailed explanation of the data collection and analysis. Methods to ensure the study's rigor and ethical considerations were also discussed. The subsequent chapter will present the study findings.

CHAPTER FOUR: FINDINGS

Introduction

The findings from the analysis of the data are presented in this chapter with attention given to the research purpose and interview questions that shaped the semi-structured interviews (APPENDIX A). A table, located in Appendix I, explicates the categories, themes and sub-themes which were delineated from the compilation of the transcribed data. These findings are presented in this chapter and are also captured in a schematic in Appendix J. The similarities that emerged from the interviews fell within four identified categories with corresponding themes and sub-themes. The role of the oncology patient navigator is multifaceted and was captured through the narratives of the twelve participants. The similarities that emerged from the participant interviews were synthesized into the themes and sub-themes. Each discrete transcript became part of a larger, more complex interpretive description of the oncology patient navigator role.

Categories, themes and sub-themes are placed in order beginning with “the participants’ unmet needs or problems encountered”, during their breast cancer illness trajectory. The next category represents “the participants’ emotional response to their unmet needs or problems encountered”, followed by the category entitled, “ways of coping”. The last category exemplifies the critical attributes of the oncology patient navigator, as identified by the participants. Prior to presenting the categories, themes and sub-themes, however, demographic information concerning the participants will be illustrated.

The Participants

A purposive sample of twelve women was recruited from various CancerCare Manitoba sites including: Breast Cancer Centre of Hope, MacCharles Cancer Care site and St. Boniface

Cancer Care. Participants were also recruited from CancerCare Manitoba's Community Cancer Program Network (CCPN) located in the rural domain of Manitoba. The participants' age range was between 36 and 49 with a mean age of 43. Four patients lived in the rural domain while eight lived within the city limits. The rural domain for this study is defined as those living outside the city of Winnipeg. At the time of the interviews, all participants had been diagnosed with breast cancer within the last three years. One patient was just diagnosed and awaiting surgical treatment, while six were undergoing chemotherapy or radiation, and five had completed their treatments. Of the twelve participants, nine had children. The participant demographic data is summarized in Table 1.1

Table 1.1 Participant Demographics

Participant Demographics	
Age	36-49 years (mean = 43)
Rural	4
Urban	8
Married/Common Law	10
Point on Continuum	Newly diagnosed – 1 First Line Treatment – 6 (Chemo:5, Radiation:1) Survivorship - 5
Have children	9
Children under age 16	7
Children over age 18	2

Unmet Needs or Problems Encountered

All interviews commenced with each participant narrating their story of how they were diagnosed with breast cancer. The first category was gleaned from all interviews as participants described a complex matrix of care influenced by contextual factors. Each participant was asked if they had experienced an unmet need during their treatment trajectory. Most participants offered a detailed account of an "unmet need"; however, some participants identified a salient problem they had encountered or an "unmet need" later in the interview process. Four themes were identified under the category "unmet needs or problems encountered": i) informational, ii) unanswered questions, iii) lack of emotional support and iv) lack of coordinated care.

Informational

A diagnosis of cancer is an extremely anxious time for patients and, in all cases participants recounted their sense of shock that transpired during their diagnosis. All participants described a variety of informational difficulties related to their breast cancer trajectory. As the participants described their diagnosis and treatment stories, they frequently included a detailed account of the difficulties related to understanding the information related to their diagnosis or treatment plans. Some patients experienced informational gaps concerning their surgical procedures or the extent of their diagnosis, including a rural patient who spoke about confusion around her treatment. She stated:

> P) He (the doctor) said I could do the lumpectomy and then do the radiation and chemo. If I just did the lumpectomy is what he told me.
>
> R) OK.
>
> P) Is what he told me. If I did the lumpectomy, I would have to do the chemo and radiation and I thought he said if I did the mastectomy, all I would have to do is the radiation and then when I did the mastectomy, it ended up I still had to do chemo and then my radiation.

Many times, rural patients diagnosed with breast cancer may be advised to undergo a mastectomy which could potentially eliminate the requirement for radiation follow-up. Due to the travel burden associated with radiation, this option may be more desirable for some patients. However, patients must be informed that despite undergoing a mastectomy procedure, the possibility remains that radiation may still be recommended and required to reduce their chance of recurrence. Perhaps this participant was informed of this possibility prior to undergoing surgery, however, her narrative elucidates a critical gap of assuming information exchanged is understood and retained.

The participants commented on factors that may have contributed to their difficulty understanding information which included: the vast amount of information provided over a short period of time, the sense of learning a "new language" related to their diagnosis or treatments and times of heightened uncertainty, which is known to affect information retention or comprehension.

Another patient shared her story concerning a lack of information regarding radiation treatments. She gave a detailed account of a debilitating skin infection which kept her from returning to work, extreme pain and accompanying fatigue. She commented on how this unpreparedness negatively affected her:

> …Everyone told me that once you have gone through chemo, that radiation was a walk in the park. And so, that was what I was expecting…I found that the radiation part did not have as much information available…So, um, and even my radiation oncologist I found that the information was just not there.

Another participant undergoing chemotherapy at the time of the interview, told her story involving a bilateral mastectomy followed by immediate reconstruction and the difficulties associated with her reconstructed breasts. She stated that she requires an additional surgery due to the missed information related to reconstruction:

> Um, we completely, both of us completely missed abdominal tissue is four times as dense as breast tissue, so when you have your breast reconstructed and you say yes, I would like to be the same size, well now they're as heavy as if you're fully engorged breast feeding, like that's how I feel all the time.

Unfortunately, once this patient has completed her chemotherapy treatments, she will undergo further surgery to reduce the weight of her newly reconstructed breasts.

Another patient described the difficulty she encountered due to perceived "missing information" she should have known and understood, before undergoing an extensive reconstruction surgery. This participant described receiving a test result confirming that her cancer had metastasized. This was unfortunately given to her after she had undergone the surgical procedure. Sadly, this participant stated that due to difficulties with healing from the extensive surgery, her chemotherapy was delayed for an additional two months. In this case, the missing information was crucial and would have influenced her surgical decision, given the extent of her disease.

The unmet theme of informational support also emerged as participants spoke about their desire to have more interaction with their medical or radiation oncologist during their treatment time period. Some participants felt that more interaction with their physicians would have facilitated their understanding of their treatment side effects and may have prompted discussions related to emotional support. Some participants felt that the lack of interaction with their physicians during their treatment times regrettably led to problems that could have been prevented.

Unanswered Questions

The next theme, unanswered questions, emerged as participants described their need to have questions answered, but in many cases, the need remained. This theme differs from the informational theme, as many patients had clearly formulated their questions but were unable to obtain answers. One patient recalled her experience as she requested assistance through the surgical treatment decision making process:

> I first asked the doctor, I said now if this was your daughter what would you recommend to her? So, I guess being in the position he's in, he didn't recommend anything because I guess there are people out there who come to him so I had to choose and I had no idea where to go or what to do and so right away I started calling people who had gone through it, the odd person I knew. I had a sister in law and an aunt (who went through it). I bought some books because I didn't do the internet thing, trying to decide, basically I had my mind made up to have a mastectomy and then I talked to one person and I thought, well she went for a lumpectomy and she's fine, so maybe that's what I'll do. My mind was changed at the last minute.

Another patient described her obstacles related to questions she had posed during her diagnostic and treatment decision making experience. She and her spouse were asking questions but were unable to gain answers during her appointment:

> So, we would be kind of wanting a little bit more and probing a little bit more and it's like they didn't quite know what to do with us. I mean not that I mean we could also go and look up information but when you have the doctor or nurse right there, it's good to sort of engage and take that opportunity to engage in that conversation. Not that we wanted to waste their time or ask frivolous questions…

A rural participant and her spouse recounted the difficulty they experienced when trying to obtain answers related to her treatment trajectory:

> Just trying to get answers. More like, just waiting, always, you're always having to wait. Like it seems you would phone somebody and they would tell you they would call you back and you wait and wait and wait and then you're phoning again and the worst thing is my husband would get upset and that and I don't blame him because he's been good for me for doing all that, but it's like he says, why do you have to be like that to get answers?

Her husband stated:

> I don't think there's enough consulting done after you're diagnosed with it…I don't know the doctors are booking these places for every 15 to 20 minutes, so after 20 minutes they take a little peek out of the corner of their eye and see the 20 minutes is up, so maybe that's enough, or go as high as half an hour and then standing up and shaking your hand and you still have questions left.

Other participants commented on not knowing what to ask during their appointment times or feeling rushed by the doctor during their consultations. This impeded their ability to ask questions and understand the information being provided by their doctors. Some of the additional problems experienced by the rural patients in this study included the driving distance to the city for additional tests, driving within the city, and not knowing where to park for appointments. Other problems included the distance to the closest treatment facility and the lack of resources such as support groups in the rural areas. Some of these obstacles remained prevalent throughout the entire treatment trajectory.

Lack of emotional support.

The need for emotional support is essential when facing a diagnosis of breast cancer. The next theme entitled “lack of emotional support” emerged under the category, “unmet needs or problems encountered” as patients recounted emotionally turbulent times when support would have been valuable. Some participants highlighted the need for emotional support not only for themselves but also their partners and/or children. One participant shared her concern for her spouse:

> P) As far as support for caregivers it doesn’t exist.
>
> R) Okay.
>
> P) And I know that that is something that my husband found very hard because everyone asks how I’m doing or worries about how I’m doing but who cares how he’s doing and he’s trying to do work and kids and worry and health and make sure I’m on track and that was hard.

Another participant, who was currently going through chemotherapy at the time of the interview, conveyed her concerns about her family:

> P) I am more worried about the people around me. I think I’m kind of looked after, like I’m worried about my husband and my daughter still.
>
> R) Emotionally?
>
> P) Yes. I know there’s a group for kids…(but) you’re going to have a lot of kids that (whose parents) have terminal cancers they’re dealing with…I don’t think I want my daughter there.

She then spoke about her husband’s emotions and the difficulties they were experiencing:

> P) And my husband being a guy originally just wanted to fix it and couldn't fix it…there was nothing he could do and nothing he could help with and nothing to make it go away. And now we just hardly even talk about it almost.

Another patient commented on trying to reach out for support but being unable to find it:

> P) You don't always realize that you need them or you wouldn't admit that you need them and then suddenly you're up to your ears and you say okay, I need someone, but the wait list is a month, and you're like no, no, I need someone right now…because that is always the thing, we have this program but you can't get in until 2013, or we have this program, there is a long wait list and we'll call you…

Some patients spoke about their need to "survive" the harsh treatment process and attend to the "emotional side", once treatments were finished. One patient who had finished treatments described this process as follows:

> P) I don't think I really talked to anyone until I was finished my treatment…I don't know if it's because you're so involved doing everything that you don't really have time to stop and think, but once you're through it all, that you know (pause), you start…(pause)
>
> R) Ya.

Another participant, who was undergoing chemotherapy at the time of her interview, described a similar view of seeking emotional support as soon as her treatments were completed. She said that she did not need to "start digging around on another level at this point" in the process:

> I mean right now, it's all about getting through the physical and not, unless I felt that it was a big barrier to making it through all that, that I would be talking to someone else, but I just think I'm tired and I just need to get through this.

Another patient, who was a young mother, described a constellation of emotional difficulties she endured during the diagnosis and treatment stage. She explained:

> P) Women can suffer from emotional difficulties during their treatment, there's a lot of ups and downs. I mean, you go through losing your hair, sometimes weight gain that you haven't experienced in the past. I think just emotional highs and lows, you know, with hormones, because when I started treatment, my period stopped so I think for me when your hormones are going up and down as well as trying to get through the therapy, so maybe at that time. Because I don't think anyone really told me that, I mean you assume it's going to be emotionally difficult…They have a little form that you fill out (at each chemo appointment) and on there you rate it 1 – 10 and it does ask about emotions.
>
> R) OK.
>
> P) It's not worded that way but…
>
> R) And how did you rate yourself at that time?
>
> P) Oh, I rated myself usually at a 5 or lower.
>
> R) Oh really. Did anyone follow-up with you?
>
> P) No. They talked to me about that and they spoke to me about the numbers but never really, no, they showed concern but never referred me anywhere.

Unfortunately, this young mother was not connected with psychosocial oncology until her treatments were completed. Some patients spoke about being connected with psychosocial oncology during their chemo treatments and had wished they had connected sooner.

The diagnosis and surgical phases of breast cancer are also emotionally difficult times for many patients. One participant described being "terrified" as she faced the emotional difficulties associated with surgery and treatment decision making:

> P) They gave me a lumpectomy and a node biopsy and that was a pretty horrific experience. Having to walk into the surgical room myself was terrifying. They would not give me a sedative until I was on the table.
>
> R) Oh goodness, ok.
>
> P) It was really unpleasant.

This same patient spoke about her experience with chemotherapy:

> P) It was really, really harsh. Horrible! Way worse! I cry a lot and I lost tons of weight.

Another patient recounted her diagnosis and the lack of emotional support that was provided to her during that time. She recalled her appointment for a biopsy and was not expecting to be given the diagnosis at the same time as the procedure. She stated:

> P) (The Dr.'s name) who was doing it (the biopsy), he just said, "This has to come out". I sat there silent and then said what do you mean it has to come out? What do you mean? He said, well it's malignant. And I just said oh!
>
> R) Oh my goodness.
>
> P) And he had his back to me and he was sort of fiddling doing some paperwork or something and I was just so taken aback and I thought maybe afterwards, and even actually almost immediately I thought maybe they thought I knew already and this was just standard…it was so scary, quite shocking actually…he just didn't seem to either really care that much that this was a huge revelation to me or he didn't seem to be that aware.

This same participant spoke about the emotional difficulties associated with her "physical changes" and body image after her surgery and had not received emotional support. She described her experience as follows:

P) I have to admit, I haven't, I have only intentionally looked at my breast once, I have caught a glimpse of it a few times by accident and I have not looked at my incision (crying).

R) No? Okay. It's a huge change.

P) I know I have to do it but I just have a mental block about it (crying).

She shared further emotional difficulties related to her hair loss and the loss of a scar on her body that was removed during her surgical procedure. She felt that her body had been exceedingly altered as a result of her surgery and reconstruction related to her breast cancer.

Lack of coordinated care

The diagnosis and treatment trajectory for breast cancer occurs in a number of facilities with a variety of healthcare professionals providing care and consultation. This can lead to a complex labyrinth of care for patients and their families. The theme, lack of coordinated care, emerged from the descriptions of the participant's experiences as they progressed through their care trajectory. They provided detailed accounts of their diagnosis and treatment stories highlighting uncoordinated care as a major burden. Some participants experienced delays in their diagnosis or treatments whereas other participants commented on the confusion surrounding their treatment or diagnostic testing. In particular, two rural patients experienced delays in diagnosis, consultations and treatments. One rural patient who carries a genetic mutation increasing her risk of developing breast cancer, and whose grandmother, mother and sister had died of breast cancer was told that the lump in her breast was 'nothing to worry about'. Four months later, a lump developed under her arm which led to the diagnosis of her breast cancer. The participant's spouse commented first with her response following:

> S) It just seems like treating it is stretched out over like just about a year and a little bit, it will be a year.
>
> P) my first one I guess, so four months before they finally got everything together where I could start my chemo or anything…ya, because I started in April and it's April and I'm just going to be starting my radiation…

She recounted an episode of uncoordinated care and confusion concerning additional tests:

> P) I got a letter from him (her doctor) saying that he wanted to have another telehealth with me and I'm thinking, I just had a telehealth with you last week, why would you want to have another one? So I phoned down to (doctor's name) office and I said, well we just had a telehealth last week, why are we needing another one this week?
>
> R) Ya.
>
> P) And she said well he wants to see you after the CT scan and I'm thinking what CT scan? And she goes did you not have a CT scan? And I said no. And she said well it was sent to (rural town). And I said well no one has ever phoned me to tell me that I needed a CT scan. So that was lost, so that was another two weeks before they set it up again…

Another rural participant went to a few doctors before she was diagnosed with her breast cancer which added to her delay in both diagnosis and treatment. One rural doctor told her to wear a tighter fitting bra. She commented on her delay stating:

> P) I had gone through obviously a few doctors and so when I went for the chemo the first thing my chemo oncologist said was why did it take me so long to get here where I was? And I proceeded to explain to him what happened when I went to (rural town) and he was

> quite concerned about this and said that this doctor should know and all I wanted to do was move forward not move backwards.

Navigating the oncology system and knowing the next steps in the breast cancer treatment trajectory were also challenging for the participants. A young mother recalled her experience with a lack of care coordination as she made many phone calls and did not understand the treatment trajectory. She stated:

> So I was, it was probably about seven weeks after I had the mastectomy and I think I had gotten my results back so I was calling the oncology desk and the um, um, for chemo therapy I was calling the radiation oncology desk, I was trying to figure out what my next steps were and I couldn’t really get anybody. I kept getting a clerk who said you know someone will call you back and I didn’t know, would they do chemo first or radiation first or what’s gonna happen…

The diagnosis and treatment trajectory for younger women with breast cancer is multifaceted and riddled with a constellation of unique needs for each individual. Women who undergo treatments for breast cancer are often fraught with well known side effects including pain, nausea, weight loss, alopecia, fertility concerns and fatigue. These side effects along with the life-threatening disease of cancer increase a patient’s sense of vulnerability.

Emotional Reaction to the Unmet Needs or Problems Encountered

The next category entitled, emotional reaction to the unmet needs or problems encountered, represents the barrage of emotional turmoil generated when the participants experienced a variety of inconsistencies including diagnosis or treatment delays, unanswered questions, informational gaps or lack of care continuity. Notwithstanding these obstacles, many emotional needs remained unmet for the participants and their families. During the interviews, the participants recounted some of their unmet needs or problems encountered during their illness trajectory and some described their reaction. For other participants, feeling states or emotional responses emerged during the interviews through careful consideration of their body language, verbal tone, and storytelling. Four themes were generated under this category, which include: i) uncertainty with a sub-theme of frustration, ii) anxiety, iii) powerlessness, and iv) vulnerability.

Uncertainty

Emotional uncertainty penetrated the narratives of many participants as they described their confusion around who to call, and what to expect concerning treatment options or diagnostic tests. One participant, who was going through chemotherapy at the time of the interview, described her uncertainty as she felt there was no one "in charge" of overseeing her course of treatment:

> I don't feel right now that there's one person kind of watching me, but I did feel that in the beginning because I saw the doctor and the nurse on the same day when they told me the treatment plan…I just sort of feel now, in the beginning I really felt like this was a team looking after me and now, it's a little bit looser I guess.

Another participant recounted her feelings of uncertainty related to her course of treatment:

> I just know at that one point I thought I think the system has kind of forgotten about me (laughs) and so it was, it was kind of at that point that you want to be able to call someone and say ok like I know I talked to these clerks and they just say my name's been given to somebody but they can't give me that person's name and my file is somewhere

> but I don’t know where it is…it’s just looking for that reassurance that things are still moving along.

She continued to describe her feelings of uncertainty when she recounted a conversation she had with her oncologist:

> P) I had said though typically how long do you wait between ending of chemo and beginning of radiation? And she said oh no, you don’t need radiation. And I said, no I do. She said no you don’t need radiation. And I said yes the margins were very narrow, I need radiation. Then she looked at my chart and she said oh yea, you do need radiation. And it’s like ah! (laughs) I shouldn’t be the one having to tell you this.
>
> R) Yes.
>
> P) It doesn’t engender a lot of confidence, you know?

Another participant described the inner turbulence and uncertainty she was feeling as she endured her treatments. She spoke about her “episodes” of crying in her car:

> P) It was hard to find people who could tolerate hearing those (sad) thoughts. So when I was at work, I was supposed to focus on work and I didn’t have any problems focusing on work and when I was home, I focused on the kids and I didn’t have any problems with that. And I would sort of have my crying episodes or sad episodes driving in the car to and from work…Cancer doesn’t care if you’re a parent of a little kid. It doesn’t mean anything. So I would constantly be thinking if I survive a year, she’ll be able to have some memories of me and he’ll be able to have a lot…I remember thinking, is it worth buying a winter coat? Am I going to get more than one season out of it?

It was in the context of this narrative that this participant shared a poignant exemplar of the uncertainty and the deep rooted sadness that occurs as young mothers endure the diagnosis and treatment for breast cancer.

Frustration

The emotional response of "frustration" emerged as a sub-theme under the theme of "uncertainty", as patients told their stories. A rural patient and her spouse spoke about their frustration and uncertainty surrounding the next phases of treatment:

> P)…so he (the doctor) kind of said I'm done with you. How can he say I'm done with you when you're still going to do your radiation for your breast and your lymph nodes, which is what I'm going to have my radiation done on, so isn't he still part of it?
>
> R) Did you ask that question back to him?
>
> S) No.
>
> P) No.
>
> R) Okay.
>
> P) I guess it just didn't pop into our…
>
> S) I guess he just thought he was done.
>
> R) Yup, and he is. But do you have anybody you can call now?
>
> P) No. So who do you call?
>
> S) I don't know. I'm done.

This narrative explicitly indicates the participant's frustration with the care she received and the lack of a follow-up care plan.

Another patient described an incident that occurred while she awaited her radiation appointment. She witnessed an elderly man from a rural environment using coarse language related to his care and seemed confused as to why his hair had fallen out. The participant felt that he was afraid and uninformed. With hopes of seeing him the next day, she brought him a toque. She was able to give him the toque and explain the side effects of chemotherapy. She narrated the sadness and system frustration she felt:

> I'm wondering how many other people are not getting this information….A lot of people are scared. I'm not scared. I know my cancer is curable, it may come back but it's again curable with surgery…but people don't know these things? Why don't people know these things? I don't understand why people don't know these things? I can understand the elderly not knowing these things because they're not computer savvy, but their doctors should be telling them this stuff. Somebody should be sitting down with them explaining to them, this is going to happen, this is what your side effects might be, you know, and this is how it's going to go.

Anxiety

All participants described periodic incidents of the next theme, "anxiety" as they endured the diagnostic and treatment trajectory. Anxiety was fueled by a constellation of events including mistrust in the system, missing information, unanswered questions and inconsistencies in care. One participant who experienced delays with her diagnosis described how the obstacles led to her mistrust in the system:

> I had a lot of anxiety about whether people were, you know I had to, you know, I don't necessarily trust the system because it didn't work for me right from the beginning…

She recounted an event with a lost report:

> When I was sitting outside the surgical suite that morning to have my surgery, the resident had my file and he's like, I can't find your pathology report from (clinic name) and I'm like, of course you can't…

Another participant felt anxious as she spent hours on the internet troubleshooting her health concerns and side effects from treatment. She stated:

> P) I didn't know that I could be scheduled to come in (before chemo) and get hooked up with five bags of fluid before I ended up in the hospital. So, there's lots of things you don't know. I didn't know that I could contact them and they would put me in touch with a nutritionist. I was busy looking up all the ways to cure the problems that I was having online because I didn't know who to contact.

Powerlessness

The next theme entitled, "powerlessness", emerged from the accounts of some participants that depicted their experience as they attempted to gain some control over their care. One participant made reference to informational needs and the sense of powerlessness she felt when she had an encounter with her doctor. She was interested in obtaining information concerning nutrition:

> P) My partner asked is there any consideration we should be giving to diet or just increasing certain or changing, (pause) so that she's getting more nutrition, just as she goes into chemo. And (doctor's name) just said no, just eat what you crave and just eat normally…I just think that there is a place for more, I think it's the one place that someone who is going through this can feel like they have a bit of control in that they're contributing to their own care…you know, it's really one of the few things that maybe you can do.

Unfortunately, this participant did not connect with the local dietician as she felt "shutdown" by her doctor's words. Despite the participant's desire for control, the doctor's words seemed to take precedence.

Other facets of powerlessness delineated by the participants included difficulties understanding medication side effects and a lack of decisional control. One participant described her lack of decisional control as follows:

> P) I said I wanted to have a mastectomy with reconstruction. I didn't want any chance of it coming back and they said no. You're not allowed to have that. Even though I was told that was part of my options…That seems to be with a lot of it. I feel like I have a choice but then there is no choices the way it is.
>
> R) OK
>
> P) You can have this kind of surgery or this kind of surgery or this kind of surgery, no you're having this one.

Vulnerability

The final theme, "vulnerability", pervaded some of the participants' responses as participants described their sense of a lack of support provided by their healthcare team. A participant explained how she felt at the end of her treatment:

> P) The minute treatment is done, it's like the rug gets pulled out from under you and attention is turned off…but I found right after was extremely difficult…So you sort of get that feeling that the day treatment's over, they kind of forget about you and you're on your own…all of a sudden there's nobody answering your calls, if you have a question or, so, I did find that, I still find that difficult.

Another patient, who described severe reactions to her chemotherapy which resulted in numerous hospitalizations, rendering her unable to complete her prescribed course of treatment, commented on her feelings of vulnerability as follows:

> My doctors and nurses never called to follow-up to see if I was having issues with my chemo after they knew I was having issues. I never received a follow-up call after my surgery to see if I was having problems and I understood I was supposed to have a follow-up call to see how I was doing.

The participants' emotional reactions to their unmet needs resulted in a myriad of responses previously identified above. Their reactions set the stage for their multifaceted ways of coping through the various stages of their breast cancer treatment.

Ways of Coping

This category exemplifies the participants' ways of coping, or measures taken, to relieve the plethora of negative emotions generated by their perceived unmet needs or problems encountered. Three themes emerged under this category as follows: i) the relentless pursuit for answers, ii) becoming the squeaky wheel and iii) avoidance. The themes will be presented along with the participants' supporting perspectives.

The relentless pursuit for answers and becoming the squeaky wheel

The themes "the relentless pursuit for answers" and "becoming the squeaky wheel" are presented in this following section. These themes were constructed from the descriptions of the participants' experiences during their breast cancer treatment. A participant and her spouse commented on their biggest challenge throughout their breast cancer experience as follows:

> R) What would you say, has been your biggest challenge throughout your experience?
>
> P) Just trying to get answers…

> S) You've got to be downright (pause), a little bit on the miserable side, and then they say well he's a real pain…we held a meeting with a few of the people and I had a couple of them crying when I was telling them a little bit of the story (about the cancer) and that's when things started happening…

Another participant commented on her relentless pursuit for answers related to side effects of treatment and medications:

> There's a lot of things you don't know. I didn't know that I could contact them (oncology staff) and they would put me in touch with a nutritionist. I was busy looking up all the ways to cure the problems that I was having online because I didn't know who to contact.

Other participants recounted the need to persistently phone their physician's office to ensure their pathology report was being generated due to the wait time they were experiencing. Additionally, some participants described their pursuit for answers related to their disease trajectory and their next course of treatment as described under "*quarterbacking my entire journey*".

Avoidance

The last theme of avoidance emerged as many participants recounted a variety of times when their emotional difficulties or informational delays became too much of a burden to face. One participant recounted the emotional turmoil she experienced throughout her treatment but seeking help seemed too difficult:

> I needed help getting through the emotional stuff that I had pushed down throughout the treatments…I wish I would have had someone during my treatment time. You know? I

> think that would have helped me then to not maybe have the backlash at the end. I think I could have dealt with the emotions during instead of bottling them until the end.

Other patients avoided pursuing emotional support for family members due to various reasons including difficulties associated with finding information related to caregiver support and problems related to support group wait times.

The above descriptions reveal a constellation of coping mechanisms that were fuelled by the effects of the previously delineated unmet needs or problems the patients and their families had encountered.

Description of the Oncology Patient Navigator: Critical Attributes

The depiction of the oncology patient navigator role will be explicated by employing two themes parsed from the narratives. The first theme, “the processual facets” will be presented. This includes the most critical areas related to the process of navigating the oncology health care continuum where navigation could provide the most benefit. Five sub-themes emerged under the theme “the processual facets” which include: i) assigned to me at diagnosis, ii) managing the connection, iii) mapping the process, iv) provide practical support and v) quarterback my entire journey.

Secondly, the theme entitled, “personal qualities: the essentials” will be discussed as articulated by the participants. This theme includes three sub-themes: i) empathetic care tenor, ii) knowing the cancer system and iii) understanding the medical side of breast cancer. As previously stated, eleven of the twelve participants were unfamiliar with the term “patient navigator, thus, the question, “what comes to mind when you hear patient navigation?” was posed as an antecedent to the navigator discussion. It is important to also note that the role of the patient navigator was discussed in the last portion of the interview, in other words, after they had shared their personal stories surrounding their diagnosis and/or treatment. Consequently, this allowed the patients to reflect on how a patient navigator could have assisted them along their illness trajectory and what personal qualities mattered most to these individuals.

The processual facets

This theme expounds the system process and highlights the importance of both timing and duration of contact with the patient navigator. Five sub-themes emerged from the narratives, including: i) assigned to me at diagnosis, ii) managing the connection, iii) mapping the process, iv) practical support and v) quarterback my entire journey. These sub-themes will be presented with narratives to assist in illustrating the participants' view.

Assigned to me at diagnosis

All participants emphasized the first sub-theme and stated that the period surrounding their diagnosis was fraught with emotional difficulty and challenging to endure. This was often seen as the most anxiety inducing point along the disease trajectory dictated by events such as the shock of the diagnosis, uncertainty surrounding the process, and informational needs regarding their upcoming treatment trajectory. One patient commented:

> I think there are certain periods of waiting and you just, it would be nice to have somebody to contact and they can reassure you that you're ok, that you're in the system and that things are happening.

Many patients spoke about the shock and disbelief that occurs at diagnosis and emphasized the connection to a patient navigator during that time, would be essential. Other issues highlighting this need included informational support and the need for emotional support during this time period. One patient said:

> …there's a weird thing that happens at the time that you get the diagnosis, when you're sitting in the room. Anyone who's in that room, you're instantly connected with…To me, if the patient navigator could be there then, and the other thing too, then they hear the information that you get, so if you miss something or misinterpret something, which happens all the time, they can sort of clarify that because they know exactly what you were told. To me, that would be the best case scenario, is to have that person there from the time you enter that system, wherever it is that you enter the system.

Another participant also spoke about having the patient navigator assigned to her at diagnosis as follows:

> I think you should be assigned someone because you don't always realize that you need them or you wouldn't admit that you need them and then suddenly, you're up to your ears and you say, ok I need someone. But then the wait list is a month, and you're like no, no, I need someone right now.

Another patient commented on the shock she had felt upon her diagnosis and felt the patient navigator could have provided support during that time:

> Once I was diagnosed and I left in total shock and disbelief from my doctor's office, if I had somebody that I could, that I was assigned to right then and there, that would have been great. Yes, that would have been ideal.

Managing the connection

The next sub-theme emerged as the participants described the necessity of frequent connections to the navigator. The initial period of diagnosis and treatment decision making was important thus, resulting in a higher contact frequency with a tapered contact as their treatments progressed. It is important to note that the participants emphasized that their connections with the patient navigator may be more frequent during times of uncertainty, transitioning to other care providers or as they transitioned back to their family physician following their treatment. One patient commented:

> It would be someone that you would need to meet with once a week or once every two weeks, often enough so that there was a connection so that if there was a new paranoia (laughs) you could fix.

Another patient highlighted certain points along the trajectory that would have been important to have someone to check in with:

> I don't really know what my follow-up is? Am I done? I walk out the door and you see me every six months like, that's it? So I think those are the big points, before each stage of treatment starts, and then in the middle, and then at the end for sure, and then again, maybe after follow-up.

Most participants described their vision of communication with the patient navigators as having the navigator periodically reach out to them as opposed to the participant always having to contact the navigator. Emotions such as, "being too scared to call" or not feeling well enough to call, surfaced during the interviews. One patient said:

> I know that some days you're not feeling the greatest and unless the phone rang, I wouldn't make calls to people.

Another patient commented:

> You know, if you're not being called, you may not reach out, so having like every two weeks or something, having them call and just say how's it going, is there anything that you need some assistance with? Or where are you at? Or, where do you think you're at? I mean they would know, they would probably have access to your chart.

Another patient stated:

> I think somebody that contacts me…you know, the doctor said you'll be getting a phone call from someone about ways to meet with you and help you through this process. That would be wonderful.

Mapping the process

The next sub-theme entitled, mapping the process, was related to the participants' descriptions of uncertainty they had endured as they tried to navigate their way through their treatments. Mapping the process emerged as an essential role for the patient navigator. One patient described her processual complexities as follows:

> It is a very complicated process because you can come in at all different points along the way…people don't know the difference between a medical oncologist, a radiation oncologist, who you see for what, what the surgeon does, all of those things, all of those roles, the chemo nurses, who do you call if you have an issue happening, who do you call?...so to me a patient navigator would possibly be someone who helps you with all that, with the system and what all of the roles are in the system that helps you kind of get through the process.

Interestingly, this same participant compared the patient navigator to a midwife she had been connected with as she went through her pregnancy:

> It reminds me of the midwife I worked with when I was pregnant and even though I had (child's name) in the hospital and I had an obstetrician. I had her for support and she walked me and was with me through the whole process including afterwards, even after the delivery. So she helped me navigate through that process although it wasn't nearly as complicated as cancer but it was amazing to have that support.

Other participants described difficulties associated with understanding the treatment process, including the typical breast cancer journey treatment course, timing of treatments and where to go for additional tests before their surgery.

Practical support

Practical support emerged as a sub-theme theme under the processual facets theme as many participants felt that the oncology patient navigator could provide direction related to other aspects of care. These included links to resources such as financial assistance, transportation tips and child care arrangements. A participant in the rural area stated:

> Whatever reasons, financial reasons, or health reasons or anything, or just emotional breakdown…whatever the reason…we have established the timeline I'm ok with my doctors, I understand what the nurses are saying, all of these things are lined up, we have child care lined up, or personal care lined up, if someone was there to kind of remind you, kind of like a wedding planner let's say, oh you don't just get married or don't just have surgery, just do chemo, there are all these other things that you do that you need to be aware of. Like for me, transportation, I guess it could be anybody, even in the city, you do realize you will be going to see the doctor three times a week for how many weeks.

Another patient spoke about the need for connections and assistance with insurance companies:

We have heard about crisis child care but we haven't found it yet…I still have a few phone calls to make to see if it does exist…we are (also) dealing with insurance companies…and to have someone we could go to and say look at this stupid letter these people sent me, what can we do about it and how do we explain to them no I'm not done my chemo…

Quarterbacking my entire journey

The last sub-theme emerged as many participants spoke about their desire to have had someone they could call, who knew their “story” throughout their entire illness trajectory. A patient who had completed her treatments stated:

> Um, and who is this doctor and what does this person, and who’s in charge of my care? I mean that was a constant question, like who do I, even now, who’s the quarterback here of this team?...It’s very piecemeal. They do such a great job in the area they’re dealing with and yet it’s not piecemeal, I’m just a radiation patient, I’m surgery oncology, you know, so there isn’t anyone who kind of brings that together.

Another patient comment on the requirement to have the patient navigator as a guide throughout the entire patient journey:

> I think it would be good to have that reinforcement of a person saying you now this is what we offer (resources)…it would be great if it was possible to have them follow you throughout the treatment because I think your needs change, I think at the beginning I need support for other reasons than I did in the middle, at the beginning you’re going through different things emotionally, physically and then in the middle you’ve been accepted for treatment and you’re accepted the fact that you don’t have hair. There are a lot of things you just oh well. I think if you follow the person through their treatment you would find that they have different needs at different stages.

Interestingly, some participants spoke about the relationships that were built with the nurses during their chemotherapy and how that felt anchoring as they endured the process. Participants found it very difficult to say goodbye when they transitioned through their care to another provider. Perhaps this experience influenced this essential aspect of continuity of care throughout the entire trajectory in other words, having the same person as their patient navigator. Another participant undergoing chemotherapy commented similarly:

> I guess ideally, the same person that you call no matter where you are in the system to help you figure out what your next steps are or where you might be missing a turn or that kind of thing.

An additional participant commented:

> I think it should be the same person who follows you throughout your journey however long it ends up being. I know you can't guarantee that because people have lives too but it would be best if you could have the same person to follow you through your journey from diagnosis till the end when you say no more chemo, or two years free.

Some participants commented on the difficulties associated with many different care providers and emphasized the requirement for the navigator to be the same individual:

> If you start getting 10 or 12 different people that you're talking to…so then you have to start all over again trying to work with this person and like how long is she going to be there before, if you have too many of them, it's like, I don't know.

As illustrated, the processual facets of care can make it difficult for patients as they transition through their treatment trajectories. Despite the many efforts to provide supportive care services through the local cancer centre, patients continued to have difficulties navigating their way through their treatments.

II) Personal Qualities: The Essentials

The above sub-themes represent the participants' description of the patient navigator functions from a processual perspective. Alternatively, the following theme with corresponding sub-themes will depict the participants' perspectives of the navigator's essential personal qualities. The sub-themes include: i) empathetic care tenor, ii) knowing the cancer system and iii) understanding the medical side of breast cancer.

Empathetic care tenor

The sub-theme, “empathetic care tenor” was profoundly important to the participants. Many individuals commented on the caring attitude of their nurses and how that conveyed a feeling of safety while being in their care. The majority of patients felt that a nurse would be best suited in the role. They spoke about periods in their treatment where nurses listened to their needs which ultimately cultivated a sense of ‘presence’ that was not evident in many of the other care providers. This possibly influenced the participants as they referred to the nursing profession as most suited to the role. The essential quality of empathy emerged in many narratives including the following participant who felt that care and empathy were essential:

> So maybe that (patient navigator) would be something that the nurses do. I always find that they (nurses) spend lots of time with you and they’re concerned and interested in how things are going.

A participant’s spouse commented on the importance of receiving empathetic care from the patient navigator when he stated the following and gently placed his hand over his chest while the participant nodded in agreement:

> It all depends on the person. What the person has inside. What he or she is feeling…I think it’s in the person’s personality.

Another participant commented on the assistance she had received from a nurse educator and commented on the importance of empathy related to the patient navigator:

> There was an extra comfort there I mean, someone who has a lot of empathy for people who are going through cancer would be a bonus. I think to be working with somebody and doing something like that. Rather than someone who is just focused on bureaucracy.

Many participants reflected on the compassionate care they had received from their nurses and support staff at certain times throughout their treatments. This was essential for the participants as they endured the treatment processes.

Knowing the cancer system

Knowing the cancer system emerged as a sub-theme as many participants emphasized the necessity for the navigator to be familiar with the cancer system and the resources available. This was an essential part of the role as participants described the cancer care labyrinth that seemed to exist regardless of their treatment phase.

> I think there should be someone that needs to translate that whole system to people, not that that person can’t be supportive, of course they could, but the primary role I would see as being navigating that incredibly complicated system because people are coming in at eight million different points in time.

Another participant commented on the challenges she encountered and emphasized that knowing the cancer system was an essential piece of the navigation role:

> Just answer some of those system questions as you go along I think because often that is where a lot of confusion comes, is you don’t know who to be calling and you don’t know what your next steps are…it’s really all that logistical stuff that you’re looking for help with.

These participant's narratives indicate that the systemic complexities often become overwhelming for patients and their families thus, the navigating the system was viewed as an essential aspect of the role.

Understanding the medical side of breast cancer

An essential quality of the patient navigator also included the sub-category, "understanding the medical side of breast cancer". The majority of participants commented on the necessity of the patient navigator being someone they could call with specific questions related to side effects, pathology reports, or various physical concerns they might be experiencing. One patient stated:

> P) I chose a nurse (to fulfill the role) because of the medical background.
>
> R) Okay.
>
> P) I think they have a better window into the experience than a social worker. I think the social worker has a great idea as to what it is emotionally for a patient, but a nurse, I think, has all the information, emotional, the physical, like everything that is going on with the patient, I think .

Another patient felt that medical knowledge was essential:

> I would think that position would best be filled by someone with a medical background who could help walk you through this. So you could show them your pathology reports and say he (the doctor) explained this to me but I have lost it, I don't know what this means.

These comments illustrate the necessity for the oncology patient navigator to have in depth knowledge related to breast cancer pathology and treatment. Other participants utilized the support of their medical oncologists nurses but commented that this was missing at their diagnosis stage.

Summary

This chapter presented the findings that emerged from the interviews of the twelve study participants. Although there were unique stories among the participants, the commonalities were presented with themes and corresponding sub-themes. The findings from this study highlight that many patients continue to face a lack of emotional support, gaps in information and education as well as uncoordinated care. These challenges can often result in patient uncertainties, frustration and anxiety which in turn, results in unnecessary demands on emergency departments, nursing staff and other support services. Patients in this study placed many telephone calls to doctor’s offices, visited emergency departments or most deplorably, sat in silence as they endured their treatments. The findings from this study emphasize and confirm the complexities of the oncology care system and the need for a dedicated patient navigator role. The enhanced understanding of the unique perspectives of younger patients with breast cancer provide greater clarity related to gaps in oncology care provision and provide direction toward an enhanced person-centred approach to care delivery. The stories shared by the participants have also assisted in providing a greater sense of depth into the role of the oncology patient navigator. The following chapter will provide a discussion of the study findings with reference to the relevant, empirical literature.

CHAPTER FIVE: DISCUSSION

This chapter will discuss the study findings related to the research questions and sensitizing concepts utilized to guide this research. The study findings, in relation to the applicable empirical literature, will also be reviewed. As well, the methodological issues and limitations of this study, noted in Chapter 3, will be further discussed. Recommendations for nursing practice, education and research are identified.

The Relationship of the Findings to the Research Questions

The intent of this study was to describe and articulate the role of the oncology patient navigator from the perspectives of younger women with breast cancer. The questions proposed to guide the direction of this study included:

1) What does the role of the oncology patient navigator look like from the perspectives of younger women with breast cancer?
2) What are the perceived unmet needs of younger women going through treatment for breast cancer?
3) How might a patient navigator meet these needs?

The Supportive Care Framework conceived by Fitch et al. (2008) provided the sensitizing concepts utilized to guide this study. The purpose of this research was to explore and articulate the role of the oncology patient navigator from the perspectives of younger women with breast cancer. Included in this framework are the constructs of human needs, coping and adaptation and how these “provide a basis for conceptualizing how human beings experience and deal with cancer” (Fitch et al., 2008, p. 12).

Fitch et al. (2008) describe human needs with relation to the context of cancer and elucidate the loss of routine that is experienced through the diagnosis and treatment of cancer.

They state, “A situation may arise that creates new demands, and anxieties can begin to emerge; feelings of vulnerability can unfold together with a sense of loss of control over a situation and uncertainty about what to do (p. 12). Indeed, the participants in this study were met with an immense change in their daily routines, and in most cases, anxiety, shock and uncertainty emerged. The researcher was driven to explore the oncology patient navigator role in relation to the human needs in cancer concepts identified by Fitch et al. (2008).

The participants also described the burdens associated with the new demands of their cancer treatments and the various coping strategies utilized to somewhat ‘adapt’ to their illness situation. Some of the personal adaptations Fitch (2008) describes include, “to shift coping strategies and use alternative ones when the usual ones are not working, to identify those aspects of the event where personal control can be achieved, and to access required resources (p. 13). The researcher investigated some of Fitch’s concepts by incorporating questions related to challenges, support groups, resource connections, and informational satisfaction. The discussions from the participants assisted in framing and articulating the patient’s perspectives on role of the oncology patient navigator.

Themes and Categories

The four categories that emerged from the data which ultimately describe and articulate the participants’ perspectives on the role of the oncology patient navigator will be presented. The categories include: i) unmet needs or problems encountered, ii) emotional reaction to the unmet need or problem encountered, iii) ways of coping, and iv) description of the patient navigator: critical attributes.

Unmet Needs or Problems Encountered

As previously stated, each interview commenced with the participant's story of how they were diagnosed with their breast cancer. Often, the participants included a struggle or an obstacle within their story of diagnosis or treatment which tended to dominate the narrative. More often than not, the participants concluded their 'diagnosis story' with a positive statement such as, "that was the negative part um the rest was good and you're given a lot of places to go, suggestions…". As this particular interview progressed, the participant recounted further problems and unmet needs she experienced during her care. Other participants reacted similarly as they described obstacles or problems with their care but quickly masked their statements with responses such as: feeling *"lucky"* to have caught their cancer, or their treatment moved along quickly *in comparison* to others, or they were *fortunate* to have finally connected to some of the resources that were available. Despite being fraught by these negative experiences, the majority of participants ended their stories on a positive note.

The interview transcripts were replete with a variety of unmet needs that were identified at the onset of the interview, however a few participants were unable to find something in their journey that resonated with the words 'unmet needs'. Interestingly, as the interviews progressed, these participants explicitly captured a range of problems they had encountered but did not classify them as 'unmet needs'. Thus, in order to capture the obstacles faced by all participants, the theme of "unmet needs or problems encountered", emerged. Future studies should consider that classifying obstacles or problems as 'unmet needs' may not capture the variety of struggles patients face. Within this study, all participants identified either an unmet need(s) or problem(s) they encountered regardless of their treatment phase. A systematic review of unmet supportive care needs of people with cancer conducted by Harrison, Young, Price, Butow & Solomon

(2009) revealed that patients in the post treatment phase of care were more likely to reveal an unmet need when compared to their counterparts in other phases of the cancer trajectory. As such, the majority of participants in this study were in the active phase of treatment (chemotherapy) and identified numerous unmet needs or problems they encountered along their treatment trajectory. The most frequent problems or unmet needs consisted of information provision, unanswered questions, lack of emotional support and a lack of coordinated care. Similarly, BC Cancer Agency conducted a pilot study using a nurse and a social worker as navigators in separate sites and found that patients needs during the intervention included, "psychosocial support, help with understanding medical information, help communicating with others and practical support" (BC Cancer Agency, 2005, p.2). Similarly, a study by Carroll et al. (2009) using trained lay patient navigators randomized to a navigated group (n=19) and non-navigated group (n=16) found that the non-navigated group of patients expressed unmet needs including isolation, lack of social and emotional support, and informational requirements such as side effects of medication, treatment processes and decision making. The unmet needs of the patients in their study persisted throughout the entire cancer trajectory.

Informational. Research has indicated that information given to patients may assist in reducing feelings of anxiety associated with their cancer (Beaver, Twomey, Witham, Foy, & Luker, 2006; Hack et al., 2005). Many participants in this study identified informational support as an unmet need which contributed to their feelings of anxiety and uncertainty. The veracity of the present study findings are congruent and well-documented in the empirical literature (Bilodeau & Degner, 1997; Schofield et al., 2003; Wright, Holcombe, & Salmon, 2004). However, studies have also identified that often times, information exchanged between the care provider and patient is either misunderstood or simply not retained (Hack et al., 2005; Palsson &

Norberg, 1995). Patients often experience high levels of anxiety during diagnosis which is known to impair an individual's ability to understand or retain further information. In particular, participants in this study found that information such as breast reconstruction details, side effects of medications, nutritional concerns, pathology information and treatment decision making were unmet informational needs. Despite this, a variety of factors must be considered including the possibility of the information being given but simply not retained or perhaps not understood. It is also possible that patients may not have conveyed their difficulties with associated with information comprehension or perhaps worried about wasting their healthcare providers' time.

A study assessing the unmet supportive care needs of newly diagnosed patients with cancer (n=236) conducted by Sutherland, Hill, Morand, Pruden & McLahlan (2009) revealed that information provision was the greatest need during the diagnostic phase of the trajectory. Perhaps surprisingly, the majority of patients (>70%) rated psychological items as 'not applicable' during this time. The majority of participants in the present study had entered the treatment phase of care and expressed a need for some form of emotional support. On the contrary, one individual who had just entered her chemotherapy treatment phase expressed her need to just 'get through' treatment and then 'worry' about the emotional side of cancer once treatment was completed.

Unanswered questions. Participants in this study described a variety of instances where unanswered questions evoked frustrations and anxiety as they endured their treatments for their breast cancer. This was considered part of the participants' unmet needs in this study. The unanswered questions encompassed a variety of distinctive meanings that evoked similar frustrations and uncertainties. The participants recounted difficulties such as not knowing *what* *to ask* during their appointments, not having their questions answered and lastly, not knowing *who to ask* when they needed answers. A review article by Hack et al. (2005) indicated that younger women with breast cancer felt that information pertaining to treatment side effects, prognosis, and long term effects was paramount. Participants in this present study faced difficulties obtaining information and answers related to treatment decision making and the management of treatment side effects.

Some participants in this study also recalled other aspects of unmet informational needs and unanswered questions related to their reconstructive surgery and the side effects of treatment. One participant commented on feeling ill prepared as she began her radiation treatments which quickly became debilitating for her. Four other participants felt unprepared for their reconstructive surgeries with two stating they would have waited until after their chemotherapy treatments if they would have been better educated about the process and recovery. Similarly, a study conducted by Freedman (2003) found that patients who underwent immediate reconstructive surgery felt that the side effects of the surgery were “greatly underestimated” (p. 327). This led to a sense of mistrust between the patient and healthcare provider.

Lack of emotional support. Approximately 30% of patients who undergo treatment for cancer develop psychological morbidity (Carlson & Bultz, 2003; Zabora et al., 2001). Thus, emotional support must be offered and the need for it should be assessed as younger women endure the breast cancer treatment trajectory. Del Mastro et al. (2006) found that younger women often have concerns related to loss of fertility, psychosocial difficulties and menopausal side effects. Sammarco (2001) found that younger women often have heightened emotional concerns related to body image, nausea, and fatigue. Congruently, the participants in this present study had emotional concerns related to their cancer treatment and unfortunately, felt a lack of emotional support as they transitioned through their care. Some additional concerns for the participants in this study included body image disturbance, fertility issues and support for family members including young children.

Lack of coordinated care. The participants in this study reported a lack of coordinated care which resulted in a myriad of emotional responses including uncertainty, anxiety, powerlessness and vulnerability. The uncoordinated care resulted in delays in diagnoses, treatments and consultations. Participants also experienced confusion around their treatment plans and missed appointments due to the lack of care coordination. A qualitative study conducted by Wagner et al. (2010) which involved perspectives of patients, family members and healthcare providers revealed findings that closely reflect the lack of coordinated care experienced by the participants in this present study. The negative consequences associated with the lack of coordination similarly involved delayed appointments and treatment setbacks. Interestingly, a study that elucidates a large factor possibly contributing to uncoordinated care was conducted by Haggerty, Reid, McGrail and McKendry (2001). They found that oncology patients encounter a minimum of 13 physicians involved in their care trajectory and in some cases, up to a maximum of 97 physicians. Further, due to the prevalence of uncoordinated care and complexities associated with the treatment for cancer, a national initiative established by the Canadian Partnership Against Cancer (CPAC, 2011) has identified strategies such as patient navigation, to address these concerns.

Emotional Response to the Unmet Needs or Problems Encountered

The participants in this study experienced many emotional reactions related to their unmet needs and problems they had encountered during their breast cancer treatment trajectory.

Uncertainty, anxiety and vulnerability emerged as participants spoke about the difficulties they faced as they transitioned through their care. Similarly, these emotions are well documented in the empirical literature with relevance to the oncology patient population. Anxiety and distress have been found to affect oncology treatment outcomes and influence a patient's overall quality of life. (Madden, 2006; Vignaroli et al., 2006). Research has also demonstrated that anxiety and emotional distress persist throughout the entire disease trajectory for many patients with cancer (Bultz & Holland, 2006). Other emotions experienced by participants in the study included frustration and powerlessness evoked by difficulties with healthcare provider interactions and system processes.

Ways of Coping

The participants in this study utilized a variety of ways to cope with the difficulties associated with their unmet needs or problems they had encountered. In many cases, participants described their relentless pursuit for answers related to their treatment options/trajectory, side effects and pathology reports, as a method of coping with their unmet informational needs. Numerous methods were employed by the participants as they searched for information related to their cancer which included ongoing telephone calls to healthcare staff, internet utilization, PubMed searches and peer support interaction. Some participants described their need to "become a squeaky wheel" as they attempted to gain control through their treatment trajectory. Other methods of coping included avoidance in seeking emotional support for members of their family as they endured treatment and described the difficulties associated with finding information related to caregiver support. They described their avoidance of pursuing a support intervention due to the other demands associated with enduring the treatment process. Several studies have elucidated numerous obstacles related to younger women as they journey through their treatments for breast cancer including: body image and sexuality concerns, multiple role demands of both work and parenthood, and changes in relationships with partners or children (Avis et al., 2004; CBCN, 2003; Mosher & Danoff-Burg, 2005). Similarly, the participants in this present study, referred to child care demands and concerns with their family relationships.

Description of the oncology patient navigator: critical attributes.

Patient navigator roles have been illustrated by healthcare professionals and, in some cases, described by patients who have previously experienced navigation throughout their cancer journey. A patient navigator has been described as one who (1) facilitates access to care, (2) is a skilled communicator and listener, (3) is knowledgeable of the cancer system and resources in which they work, (4) acts as an empathic patient advocate, and (5) provides information and education (Pedersen & Hack, 2009). Oncology patient navigation services, as described in the literature, have not been formally introduced to the province of Manitoba thus, as previously mentioned, the participants in this study were not connected to a patient navigator during their treatment trajectory. Most noteworthy is the fact that all interviews began with the participants accounts of their experience with breast cancer. This set the stage for the succession of questions relating to the esoteric concept of the “patient navigator”. This is mentioned, as it lends itself to the veracity of the descriptions recounted by the participants. Two important facets were parsed out separately and include: the processual facets of the role and the essential personal qualities of the individual fulfilling the role. This will be discussed with relevance to the empirical literature.

The processual facets

Assigned to me at diagnosis. An important aspect of patient navigation is removing obstacles or perceived barriers to care as defined in the literature (Freeman, 1994; Shwaderer & Itano, 2007; Pedersen & Hack, 2009). The participants in this present study emphasized that the navigator should be assigned to the patient at diagnosis. Two significant concepts emerged with this statement: *assigning* patients to the oncology patient navigator and commencing the assignment at the *diagnosis phase*. This study did not explore the meanings associated with assigning a patient to an individual but one may hypothesize that patients may feel a sense of safety and security in knowing they have someone who is essentially ‘assigned to their case’. The participants described the anxiety, shock and uncertainty during the diagnostic phase which was profoundly life changing. This is well documented in the literature (Bultz & Holland, 2006; Carlson & Bultz, 2003; Doll et al., 2003). The diagnosis phase was also considered a time when the present study participants required a lot of information and education regarding their upcoming course of treatment. As previously mentioned, these findings are aligned with the literature which states that anxiety associated with the diagnostic phase often interferes with the patient’s ability to understand or retain information (Corporate Research Associates, 2004; Graydon et al., 1997; Hack et al., 2005). Most notably, the desire for the patient navigator’s assistance to be initiated at the diagnostic phase, reflected the responses of all participants in this study and may have assisted patients with treatment decision making and their understanding of their upcoming treatment trajectory.

Managing the connection. Modes of communication including email, telephone, and face-to-face consultations between the patient navigator and patient were also described by the participants. This study found that telephone connections with the patient navigator were thought to be appropriate, however, two patients stated that an initial face-to-face meeting to establish a connection would be important to them. All participants stated the frequency of connections to the navigator may be greatest in the beginning of the illness trajectory, when information needs are known to be paramount. A pilot study conducted by Beaver et al. (2006)

identified the effectiveness of a nurse-led telephone follow-up intervention for women with breast cancer. Patients in the intervention group were more satisfied with their information needs being met than the patients in the control arm. Patients in the control arm also reported high levels of psychological morbidity which was contrary to the individuals in the intervention group where patients were able to discuss ‘sensitive issues’ with the nurse via telephone. Telephone support interventions have been well-documented in the literature as a means of providing counseling and education (DeGrasse & Hugo, 1996).

Participants spoke about feelings of ‘withdrawing’ and ‘cocooning’ during the treatment phase, and diminishing their energy to reach out for assistance. Most participants would have welcomed the patient navigator contacting them periodically as opposed to sitting in silence especially during weekends or evenings which was the case with one participant. This was echoed in a study conducted by Smithies, Bettger-Hahn, Forchuk, & Brackstone (2009) performed a telephone intervention on weekends for women with breast cancer undergoing chemotherapy. Their study (n=19) found that the women felt, “that it was easier to hear information as opposed to reading it in a book… and it was useful because it reiterated important information about possible side effects and emergency contacts that may have been missed during their pre-treatment appointments” (p. 125). In the present study, some participants recounted tremendous challenges related to treatment side effects and would have appreciated telephone follow-up from a patient navigator after their chemotherapy treatment. This was considered an important point in the trajectory where a phone call from a patient navigator would be highly salient. One patient detailed her poignant story concerning her need for emotional support a few weeks after her initial chemotherapy treatment but was too overwhelmed to reach out. This participant recalled additional emotional turmoil at the end of her treatments. She felt that if she had been connected to psychosocial services earlier in her trajectory as opposed to when her treatments were over, the emotional burden she endured may not have been as profound. Navigating her way through her harsh treatments took precedence over the emotional side of cancer. The results of these findings elucidate the need for the patient navigator to periodically reach out to patients with breast cancer as opposed to assuming patients simply require a telephone number or business card to meet their needs at home.

Mapping the process and providing practical support. Participants in this study felt that mapping the cancer care process and providing practical support were also viewed as vital aspects of the patient navigator role. Participants faced obstacles such as misunderstandings concerning the ‘next steps’ in the journey and information related to, ‘what to expect’ during the next steps. These findings are aligned with the foundational rationale for the development of patient navigation as stated by the navigation pioneer, Dr. Harold Freeman, “We know we have a problem when the biggest fight for people with cancer is getting through the system. This is a moral dilemma” (personal communication, October 9, 2009). The empirical research concerning the original developments of patient navigation programs were based on system fragmentation and individuals ‘getting lost’ in the process (Freeman et al., 2004; Psooy et al., 2004; Corporate Research Associates, 2004). Most participants in this study felt lost or experienced difficulty navigating their own way through at least one phase of the breast cancer illness trajectory. Questions such as, what comes next, where do I go for additional tests or my treatments, and how long is the treatment trajectory, were paramount concerns for the participants. An absence from daily routines and feelings of uncertainty related to treatment plans are well-founded concerns especially for younger mothers who are often the parent who coordinates activities for children or child care. The role of the oncology patient navigator was thought to involve education, information and emotional support during this important time of the trajectory.

While providing educational support, the provision of practical information was also considered a valued aspect of the patient navigator role. Some participants struggled with practical information related to parking, financial support, transportation to appointments and child care arrangements.   A rural patient described being overwhelmed as she drove into the 'big city' for a treatment consultation and experienced difficulties navigating her way through a city parkade for her appointment.   The findings related to the role providing practical support are closely aligned with the navigation literature as many navigation programs have reported on the provision of practical support while patients endure their treatment course (BC Cancer Agency, 2005; Corporate Research Associates, 2004; Gentry & Sein, 2007; Long Island College Hospital, 2002; Steinberg et al., 2006).   A previously mentioned pilot study conducted by BC Cancer Agency (2004) discovered that by providing practical support in conjunction with education about medical decisions their oncology patient navigators were able to facilitate 'patient preparedness' which was an ultimate goal of their program.

Another concern related to mapping the process included assisting patients through the barrage of tests required after their diagnosis, but before surgery, and providing guidance concerning perceived delays in receiving the pathology findings. Further navigator responsibilities were delineated as one participant spoke about waiting for her pathology results and fearing, "(the) cancer was spreading while we were waiting". The navigator could provide evidence-based education and emotional support to patients during this time to assist with patient anxiety. Participants stated it would have been valuable for the patient navigator to be present during this phase of the disease trajectory.

Quarterback my entire journey. The last processsual aspect of the oncology patient navigation role elucidated in the transcripts included the sub-theme of quarterbacking my entire journey. Some participants spoke about their needs changing as they transitioned through the treatment process. One participant felt her emotional and physical needs fluctuated dramatically throughout treatment and emphasized the cathartic moment when she finally accepted the fact that she had lost her hair. These were times where the patient navigator could have provided support to her. Thus the navigator would bridge the perceived gaps during patient care transitions. One study in the empirical literature identified that patient navigation should be 'targeted to high stress phases of the treatment trajectory, that is, at the time of initial diagnosis, immediately following treatment, and at the time of recurrence or palliative diagnosis' (BC Cancer Agency, 2005, p.5). Some participants' described the transition points in their care as times when they felt they were 'starting over' and their sense of comfort had been dashed. Perhaps having a navigator during this time would lessen the difficult transition effects that are often perceived. Transition times in the cancer care trajectory have been defined as moving from surgeon to medical oncologist and in some cases, to a radiation oncologist. Some participants described a sense of melancholy that emerged during transition times as they had cultivated comfortable connectedness with their care providers which was broken when their care was transferred. Some participants even captured their sense of distress once their treatments were completed as they felt their routine of 'looking after' their cancer was lost. This was a very distressing time when participants felt that a navigator would be integral in facilitating their transition out of oncology care. The concept of continuity of care is well studied in the literature and has been found to decreasing patient's feelings of vulnerability and improve patient outcomes (Van Walraven, Oake, Jennings & Forster, 2010). Interestingly, the original patient navigation program was developed for screening services and follow-up on abnormal mammograms only (Freeman et al., 1995; Psooy et al., 2004). Since the original descriptions of patient navigation emerged, the role of the navigator has been expanded over time. The Long Island College Hospital (LICH) Breast Health Navigation Program (BHNP) (2002) hired lay patient navigators whose role was expanded from the 'point of abnormal finding to follow-up' or treatment completion. The aspects of the patient navigation role at LICH include, working with "reserved time slots in radiology, patient appointment reminder calls, in-service programs to educate staff about insurance regulations for screening mammography, report tracking, using algorithms derived by the system overcoming patient barriers to care such as child-care, life-related issues, language barriers, cultural and socioeconomic fears and ongoing information/education for the health care team" (LICH, BHNP, 2002, p.4). Although this study illustrates the expansion of the role to include the entire trajectory, the main functions of these navigators differ from the participants' perceptions of the role in this study. Another pilot study hired lay patient navigators to work out of their homes and in their communities assisting 'lower-income and medically underserved' women going through the diagnosis and treatment for breast cancer (Fouad, Wynn, Martin, & Partridge, 2010). The lay navigators followed patients through their entire treatment journey focusing on barriers to care such as informational/emotional support, financial burdens associated with care and assistance with understanding written information. The results of these studies highlight the patients' perspectives with regard to the navigator assisting them throughout their entire disease treatment trajectory, however, the needs must be tailored to each individual.

Personal qualities: the essentials.

Empathetic Care Tenor. The second part of the discussion concerning the role of the oncology patient navigator elucidates the personal qualities the participants considered essential for the relationship to be successful. Some participants reflected on the empathetic care tenor emitted by the nurses during their experience, which suggests the necessity of this quality. Merriam-Webster (2011) defines empathy as 'the act of understanding, being aware of, and being sensitive to and vicariously experiencing the feelings, thoughts and experiences of another…' It was evident in the participants' responses that 'being heard' and 'being understood' by the patient navigator was essential. Another participant spoke about the necessity for the navigator to be 'present' while the participant interacted with the individual, capturing the concepts of being 'listened to' or simply, 'heard'. Thus, conveying empathy is an essential personal aspect that many participants discussed with regard to the patient navigator role. In relation to this finding, a patient navigation review article by Robinson-White, Conroy, Slavish & Rosenzweig (2010) stated that, "navigation influence can be heavily personally influenced through the strength of an engaging personality…the individual navigator's personality and warmth may be an important component of the navigation's (program) success" (p. 131). With this in mind, the navigator should be an individual who understands patient concerns and is competent in conveying an empathetic way of being.

Knowing the cancer system. According to the participants, the oncology patient navigator is also an individual who knows the cancer system well. The participants spoke about the importance of knowing about relevant resources such as support groups, helpful websites and links to information sessions. This aspect of the oncology patient navigator remains consistent with the navigation literature (Corporate Research Associates, 2004; Melinyshyn & Wintonic, 2004). Korber, Padula, Gray and Powell (2011) also found that patients often approached the services of the navigator for links to appropriate resources and assistance with information.

Understanding the medical side of breast cancer. The last important aspect of the oncology patient navigator role, gleaned from the majority of the participant narratives, includes the ability to understand the medical side of breast cancer. Seemingly, this facet of the role negates the ability a lay individual to assume the role of the oncology patient navigator. On the contrary, two participants in this study felt that the navigator did not need to convey medical information because their nurses had been able to answer many questions for them. Despite this, most participants felt that the navigator needed to respond to the ‘medical side’ of their questions and in two cases, this could have occurred via telephone resulting in unnecessary hospital/clinic appointment times. Participants also felt that the patient navigator could respond to questions concerning pathology reports, obscure medical ‘language’, clinical trial information, treatment decision making and chemotherapy regimens/side effects. The empirical patient navigation research suggests these findings are aligned with many of the navigation programs as nurse navigators are becoming more popular due to the higher level of education required to appropriately assist patients through their cancer care trajectory (Corporate Research Associates, 2004; Cancer Care Nova Scotia, 2010; Fillion et al., 2006). Further, Korber et al. (2011) found that patients in their study felt the most important aspect of navigation was the education related to their cancer and the information on symptom management.

Oncology certified nurses have fulfilled the role of the oncology patient navigator (Bowman & Grim, 2008; Fillion et al., 2006) as well, advanced practice nurses (Ritz et al., 2000) have been mandated for certain navigation programs. With this in mind, in order to provide an appropriate assessment of patient and family needs, clinical education and teaching or perhaps trouble shooting for oncology patients and their families, it may be prudent for a nurse to assume the role of the oncology patient navigator. EduCare, a program designed for educating and training nurses to become breast health navigators has been established in Atlanta, Georgia (EduCare, 2011). The role of the nurse navigator from the perspectives of EduCare, includes the functions previously described and some Canadian patient navigation program managers are utilizing this training facility to educate and prepare their nurse navigators to assume this role (S. Bond, personal communication, June 22, 2011; S. Cook, personal communication June 3, 2011). The Canadian nurse navigation training curriculum was an inter-provincially designed program to educate nurses entering the navigation arena. This program also reflects the goals of the patient navigator previously described above.

Limitations of the Study

There are a number of limitations associated with the findings generated from this study. First, the student researcher, who cultivated the interview guide and conducted all interviews, comes with an inherent experiential and positional bias toward the direction of the navigation role. This is acknowledged. Despite being a neophyte researcher, strategies were implemented to minimize such bias and inexperience which included a reflexive journal, ongoing review of the transcripts for accuracy, and involving the expertise of a committee member during the data analysis stage.

Another limitation of this study involves the possibility of retrospective bias or response shift. In this study, five of the twelve patients had completed their treatments for breast cancer within the last three years. Despite this possibility, these five patients were able to describe recollections of their experience based on a considerable portion of the disease continuum.

An additional limitation is the sample size of twelve participants. In an attempt to increase recruitment, the sampling frame was expanded to include women who had been treated for breast cancer within the last three years as opposed to the original criteria which required women to have completed treatment within one year. The study took place over a period of ten months and despite recruiting efforts from various sources and an expansion of the sampling frame, only twelve individuals participated in the study. Of the twelve participants, nine had children however, only six had children under the age of sixteen. Younger children are more dependent on their parents, which potentially increases the demands and responsibilities of patients enduring treatment for cancer. Despite this, only six participants out of twelve represented this demographic.

Another limitation of this study is the lack of rural participants. Notwithstanding the assistance of the Community Cancer Program Network, which provides ongoing communication with the rural oncology treatment centres around the province, only four participants were enrolled from the rural domain. In comparison to patients living within the city limits where resources and tertiary care centres are often easily accessed, the rural patient experience may reveal increased difficulties with access to appropriate healthcare or limited resources. Further research is required to explore the perspectives of the rural patient population with respect to the oncology patient navigator role. Last, this study did not specifically ask the question, “How did your unmet needs or problems encountered make you feel and what could the system have done to alleviate the problem or unmet need?” These questions may have added to the richness of the interview discussions by providing further insight into both the patient experience as well as the system gaps. Despite the limitations of this exploratory study, the findings present an introduction into the perspectives of twelve younger patients with breast cancer, and provide insight into the role of the oncology patient navigator.

Plans for Knowledge Translation

According to the Canadian Institutes of Health Research (2010), “Knowledge translation (KT) is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care” (2010). With this definition in mind, the researcher will disseminate the findings of the study to CancerCare Manitoba’s Community Cancer Program Network (CCPN) via telehealth conferencing. The CCPN was designed to oversee the provision of cancer care services and chemotherapy administration for patients in rural Manitoba. Results of the study will also be prepared into a manuscript and submitted to a peer reviewed journal for publication. The study findings will also be disseminated to the Canadian Partnership Against Cancer (CPAC) as one of their primary goals is to assist in the development and implementation of national protocols for patient navigation services (CPAC, 2011).

Recommendations and Implications for Nursing Practice, Education and Research

The findings of this study provide implications for nursing practice, education and research. They include the following:

Implications for Nursing Practice

1. That nurses recognize and provide early intervention for the multi-faceted emotional and physical demands that younger women experience during the breast cancer treatment trajectory.
2. That current nursing roles be targeted for expansion to address the current gaps perceived by patients.

3. That healthcare providers recognize the difficulties their patients may face when transitioning through care. Communication, support and guidance are paramount during these times.
4. That information packages related to resources and support are provided however, a description of the patient's treatment trajectory should also be included as part of the written material.
5. That timelines for each treatment phase are provided and described to all patients during the diagnosis phase.
6. That patient and family needs are supported through all phases of the breast cancer trajectory and patient and family needs change throughout the illness trajectory and should therefore be assessed on a consistent basis.
7. That informational, educational and emotional support needs are assessed and provided on a consistent basis during all phases of the breast cancer illness trajectory.
8. That appropriate resources are introduced and described to patients and family members during all phases of the breast cancer trajectory, including the completion of treatment.
9. That comprehensive education, written material and support be developed and executed as a standard discharge for all breast cancer patients transitioning from their oncology centres back to their family physicians.
10. That referrals to nutritionists or pharmacists may enhance patient empowerment as patients may tailor their current nutritional intake and gain a deeper understanding of their medications thus facilitating a sense of control over certain aspects of their care.
11. That the Supportive Care Framework (Fitch, 2008) is utilized to sensitize and guide the delivery of oncology patient care.

Implications for Nursing Education

1. That the difficulties associated with navigating the breast cancer treatment trajectory are emphasized to all nurses and student nurses.

2. That educational institutions introduce the concept and rationale for the oncology patient navigator while emphasizing the complexities of the cancer journey.

3. That student nurses are taught to provide continuity of care and assess patient needs on an ongoing basis.

4. That educational materials are developed and provided to all oncology patients as they transition through their care trajectory. This information should be reviewed with the patient and family at transition times and should include: an estimated time period for the treatment, helpful resources during this time period, practical tips, a map indicating their treatment area and phone numbers for additional assistance during this phase of their treatment trajectory.

5. That nurse educators instruct nurses and students to regularly assess patient emotional needs/status and emphasize the importance of follow-up or referral to psychosocial oncology.

Implications for Nursing Research

1. That the findings from this study provide a basis for the development of future studies pertaining to the role of the oncology patient navigator.

2. That further research is required to gain perspectives on the patient navigator role from patients living in the rural domain as well as patients from other cultures. Other cultures may provide a unique insight into the role and how it may best serve their needs as they transition through care.

3. That future research utilizes terms such as “problems encountered or difficulties with care” as opposed to “unmet needs”, which does not always capture patients’ challenges with care.

4. That the oncology patient navigator role be further studied from the perspectives of patients with younger children as further themes may emerge based on their unique needs.
5. That the findings from this research provide rationale and guidance for the development and implementation of a breast cancer patient navigator pilot study.

Summary

This exploratory study provides preliminary direction into the development of the oncology patient navigator role. The results of this study illustrate the oncology patient navigator's vital attributes and processual facets based on perspectives of younger women with breast cancer. This research also indicates that despite the tremendous effort directed toward enhancing the care for younger women undergoing treatment for breast cancer in Manitoba, gaps continue to exist. This study provides guidance for policy makers and program managers who may be considering the implementation of an oncology patient navigator. This study can be utilized for the purposes of tailoring or expanding current roles in oncology or perhaps cultivating the development of new navigational programs to address the needs of younger women with breast cancer.

APPENDIX A - INTERVIEW GUIDE

Thank you for agreeing to meet with me. I would like to ask you a few questions about your experience with your diagnosis of breast cancer.

I also really want you to know that you do not have to answer a question if it makes you uncomfortable. I understand that it may be difficult for you to discuss your experience with cancer. At anytime, we can turn the audio tape off to “take a break”, if you would like to. No specific information from the interview will be shared with your health care providers. All information will be kept confidential and you may withdraw from the study at any time.

1. Can you tell me about how you were diagnosed with cancer?
2. Can you tell me about your treatment experience thus far? (If not previously answered)
3. What would you say your biggest challenge has been throughout your experience?
4. Can you tell me about your social supports?
5. Who do you talk to about emotional concerns?
6. Has information about your cancer, surgery, or treatment options been easy to find?
7. How did you decide on your treatment plans? Did you have options given to you by your doctor?
8. Have you been able to understand all of the information?
9. If not, what have you done to understand the information?
10. Have you been able to locate or participate in support groups or other resources?
11. How did you find out about them?
12. You have said that some of your challenges have been ____________, what do you think would have helped?
13. If I said the words “unmet needs” – What comes to mind for you?
14. What do you think is the best way for the needs you have had and described to me to have been met?

15. In the news, people have been talking about patient navigation. Have you ever heard this term?
16. (If not) What comes to mind when you hear the term?
17. (If yes) What do you know about patient navigation?
18. Who do you think is best suited to fulfill the role of the oncology patient navigator?
19. Prompts: Someone in the community who has gone through breast cancer, a social worker, a nurse, a lay person, etc.
20. How would you describe the role of an ideal patient navigator?
21. Would the patient navigator follow you along your entire treatment plan or should they help out just at certain times?
22. Would a patient navigator be someone you would access if you needed assistance or do you think navigators should be assigned to patients at their diagnosis?
23. How could a patient navigator help you?
24. Would you accept periodic calls from a patient navigator to check in with you and perhaps give you information on upcoming appointments or support services or
25. Closing questions

1) What’s next for your treatment plans?
2) What advice would you give other women diagnosed with breast cancer?
3) Is there anything else you would like to tell me about your experience?

APPENDIX B - POSTER

UNIVERSITY OF MANITOBA

Younger Women's Experiences with Breast Cancer

Have you been diagnosed and treated for breast cancer in the last three years?

Are you under 50 years of age?

You are invited to take part in a study exploring the unique needs of younger women with breast cancer in Manitoba.

Please call for further information:

Name:	**Allison Pedersen**
Title:	**Unique Needs of Younger Women with Breast Cancer**
Phone:	**204-299-7444**
Email:	**alli.pedersen@gmail.com**

This study has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba and the Research Resource Impact Committee of CancerCare Manitoba

Unique Needs of Younger Women
with Breast Cancer
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Unique Needs of Younger Women
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APPENDIX C

LETTER TO PLACE POSTERS: at Breast Cancer Centre of Hope, Grace General Hospital, CCPN Locations, St. Boniface General Hospital, CCMB McCharles Site

December __, 2009

Dear ______

I am writing this letter to request permission to post the enclosed poster at the __________________. I am a registered nurse and a Graduate Student at the Faculty of Nursing, University of Manitoba. I am currently conducting a study exploring the unique needs of younger women going through treatment for a primary breast cancer, to gain their perspectives on a new role in patient care. This study will contribute to the knowledge concerning the unique challenges younger women face and how a specific role in oncology health care may respond to those needs.

This study has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba and the Research Resource Impact Committee at CancerCare Manitoba. I would sincerely appreciate your assistance by placing these notices in visible areas of the _____________________. Please feel free to photocopy these notices, if patients would like a copy.

Once again, I thank you for your assistance. Please contact me at 299-7444 if you have any questions or concerns.

Sincerely,

Allison Pedersen RN, BN
Graduate Student, Faculty of Nursing
University of Manitoba

APPENDIX D

DEMOGRAPHICS FORM

Thank you for your interest in this study - Allison Pedersen RN, MN Student, Faculty of Nursing, University of Manitoba

What is your age? ___________________

What was your date of your Diagnosis ____

Do you have any children? ____

(If yes to above) What age are your children? ____

What is your marital/partner status? ____

What is your partner's occupation (if relevant)? ____

What is your occupation? ____

Where do you reside? ____

Distance to nearest medical facility? ____

Are you currently receiving chemotherapy or radiation therapy? If yes, please indicate which

one. ____

APPENDIX E

Explanation for Nurses or Social Workers when Introducing Study

A project is being conducted on the unique needs of younger women going through treatment for a primary breast cancer. The project is being conducted by Allison Pedersen a registered nurse and Masters of Nursing student at the University of Manitoba. I thought you might be interested in hearing about this project.

You can decide whether or not you want to participate when you speak with Allison. It is strictly voluntary. The interview will take approximately one and half hours, and will be similar to an informal conversation.

APPENDIX F

Explanation of Study via Telephone

Hello, my name is Allison Pedersen. Thank you for allowing me to meet with you (or phone you). Is now a good time to talk? As it was previously mentioned by (nurse/social work), I am a student in the Masters of Nursing Program at the University of Manitoba. I am also a registered nurse. The purpose of this project is to examine the unique needs of younger women with a diagnosis of breast cancer and explore a newly created role in oncology healthcare. This project will fulfill the thesis requirements for the Masters of Nursing Program.

If you agree to participate, I will set up a location of your choice, and a time that is convenient for you. The interview will be approximately one and a half hours in length. The interview will involve discussing your experience with breast cancer. I would like to audio tape our conversation so that I will not have take detailed notes while we are talking. There will be one short form to complete and I may take a few notes while we are talking. The information from the interview will be transcribed and analyzed with information from other women with breast cancer. I may need to call you again to clarify details from the interview. When the project is written up, the information will be grouped in such a way that it will not be possible to identify you. I may also contact you after the initial data analysis has taken place to be sure that it accurately reflects your experience and feelings.

My thesis committee member, Dr. Tom Hack from the Faculty of Nursing, and I, will be the only individuals who will listen to the tapes or read the transcripts. You are free to withdraw from this study at any time. Your participation in this study is entirely voluntary, and you are under no obligation to participate in this project.

Do you have any questions?

Are you interested in participating in this study?

Can we set-up an interview time?

Thank you for your interest in this study, I look forward to meeting with you.

APPENDIX G

CONSENT FORM

Research Project Title: Perspectives of Younger Women with Breast Cancer in Manitoba

Researcher: Allison E. Pedersen RN, BN, Graduate Student, Faculty of Nursing, University of Manitoba

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of the Research

- This research project is a thesis requirement for Allison Pedersen's Master of Nursing degree.
- To gain a deeper insight into the perspectives of younger women in Manitoba going through the treatment of breast cancer
- To assist in the development of a new role in cancer care delivery

Procedures

An interview will be conducted by the researcher, Allison Pedersen and the participant (signed below) that will be approximately one hour and a half. The researcher will ask questions regarding the participant's experience with breast cancer, her feelings throughout her treatment and her views about a potential role in oncology health care. The interview will be audio-taped and the information from the recording will be transcribed later. There is also a short demographic form the participant will need to complete and the researcher may take some brief notes during the interview. The researcher may later phone the participant to clarify a few details, if necessary, prior to analyzing the data. Additionally, the researcher will be selecting a few women who have participated in the study to initially share her findings with to ensure her analysis accurately reflects the experiences and perspectives of younger women with breast cancer. This follow-up will be done via telephone and will not take more than 20 minutes of the participant's time. The follow-up telephone call is voluntary for the participant, and will not affect your care in any way should you decide to not participate.

(Cont'd)

Risks and Benefits

There are no known risks for participating in this study.

Your participation in this project is completely voluntary. You are free to withdraw from the study at any time, and/or to refrain from answering any questions that you prefer to omit, without prejudice or consequence. **Participation in this study will not affect your care or treatment in any way.** Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification on new information throughout your participation. There are no direct benefits to you for participating in this study; however, this study will assist in the development of a position in cancer care delivery for future patients.

Confidentiality/Anonymity

You will not be asked to identify yourself by name during the interview. Your name will not be used in the final report, or in any publication or presentations based on the findings from this study. Only the researcher, Allison Pedersen and her thesis chair, Dr. Tom Hack, and a transcriptionist will have access to the information collected. No personal identification will be recorded on any data collection forms used in this study. The transcriptionist will sign a confidentiality agreement before transcribing the data. To protect your identity, the researcher will assign a code number that will be known by the researcher only. The data gathered will be analyzed along with information from other younger women with breast cancer. When the project is written up, the information will be grouped in such a way that it will not be possible to identify the participant. A typist, who will transcribe the interview tapes, will sign a confidentiality form before proceeding with the transcription of data. Interview tapes, notes and consent forms will be kept in a locked cabinet for up to ten years before being destroyed.

Feedback

A summary of the findings will be made available to participants. If you are interested in receiving a copy of the findings, please provide your e-mail address below* and a copy will be sent to you.

Dissemination

A summary of the findings will be presented to CCMB, the Breast Cancer Centre of Hope and the WHRA Breast Health Centre. Once again, your name will not be used in the final report, or in any publications or presentations based on the findings from this study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and that you agree to participate as a subject. In no way does this waive your legal rights nor does it release the researchers or the University of Manitoba from their legal and professional responsibilities. This research has been approved by the University of Manitoba's Education/Nursing Research Ethics Board and the Research Resource Impact Committee

(Cont'd)

of CancerCare Manitoba. If you have any concerns or complaints about this project you may contact

Dr. Tom Hack (204-235-2791) or Margaret Bowman at the Human Ethics Secretariat (204-474-7122) or by e-mail at: margaret_bowman@umanitoba.ca).

I consent to being interviewed:

____

Participant's Signature Date

*E-mail address (for a copy of the summary):

____

Researcher Signature Date

PLEASE RETURN ONE SIGNED COPY OF THE CONSENT FORM BY MAIL TO:

University of Manitoba

Helen Glass Centre for Nursing

89 Curry Place

Winnipeg, MB

R3T 2N2

APPENDIX H

Letter of Invitation (to be printed on U of M Letterhead)

My name is Allison Pedersen and I am a registered nurse conducting a study on younger women (aged 20-50) going through treatment for a primary breast cancer. This research study is part of the requirements of my Masters of Nursing degree. The purpose of the study is to examine the unique needs of younger women in Manitoba with breast cancer and gain their perspectives on a new role in oncology health care delivery.

If you decide to participate, the study will involve an interview of approximately one and a half hours in length which focuses on your experience with breast cancer. There is also a short form to complete. The interview will occur at a place and time that is convenient for you. All information discussed during the interview will be kept confidential. No specific information from the interview will be shared with your health care providers and your care will not be altered in any way. The study will be audio taped so that I can accurately reflect on what is discussed during the interview.

Participation in this study is strictly voluntary.

Please note that I may require a follow-up conversation to clarify a few details from our interview, if necessary, prior to analyzing the data. When the project is written up, the information will be grouped in such a way that it will not be possible to identify any participants. After the initial data analysis is conducted, I will be selecting a few participants who will be contacted via telephone, to be sure the data accurately reflects the feelings and experiences of the participants.

My thesis chair, Dr. Tom Hack, Faculty of Nursing, University of Manitoba, and a typist who will transcribe the interview, will be the only individuals who will listen to the audio tapes or read the transcripts from the interview. The transcriptionist will sign a confidentiality agreement before transcribing the interview tapes.

This study has been approved by the Education and Nursing Research Ethics Board at the University of Manitoba and the Research Resource Impact Committee of CancerCare Manitoba.

If you are interested in speaking with me about the possibility of participating in this study, please contact me at 299-7444. Please leave a message on my confidential voice mail if I am unable to answer.

Kindest regards,

Allison Pedersen RN, BN, Graduate Student, Faculty of Nursing, University of Manitoba

APPENDIX I

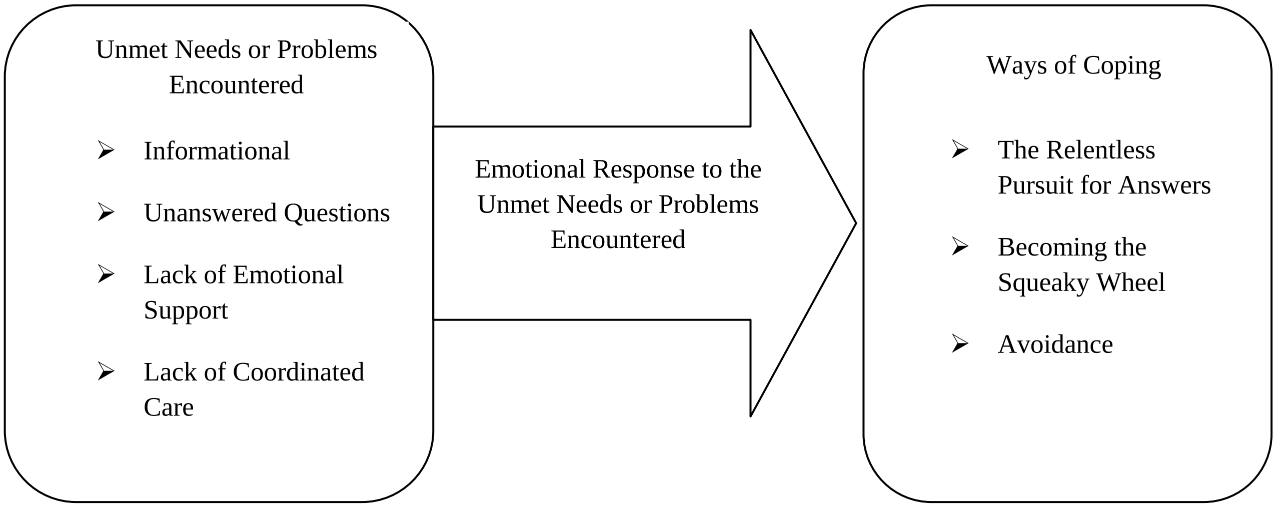
The Role of the Oncology Patient Navigator:
Perspectives of Younger Women with Breast Cancer

Unmet Needs or Problems Encountered	**Emotional Response to the Unmet Needs of Problems Encountered**	**Ways of Coping**	**Description of the Oncology Patient Navigator: Critical Attributes**	
Informational	Uncertainty: Frustration	The Relentless Pursuit for Answers	**The Processual Facets**	**Personal Qualities: The Essentials**
Unanswered Questions	Anxiety	Becoming the Squeaky Wheel	Assigned to me at diagnosis	Empathetic Care Tenor
Lack of Emotional Support	Powerlessness	Avoidance	Managing the Connection	Knowing the Cancer System
Lack of Coordinated Care	Vulnerability		Mapping the Process	Understanding the Medical Side of Breast Cancer
			Practical Support	

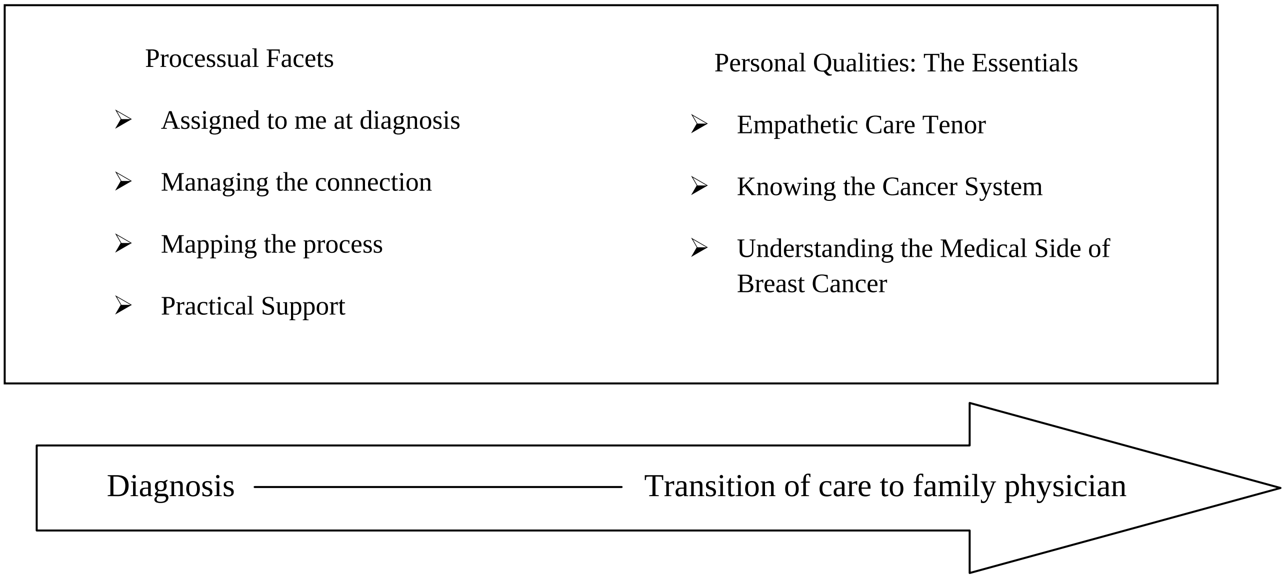
APPENDIX J

The Role of the Oncology Patient Navigator: Perspectives of Younger Women with Breast Cancer

The Oncology Patient Experience



Oncology Patient Navigator Role



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