

# An Exploration of the Patient Navigator Role: Perspectives of Younger Women With Breast Cancer

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An estimated 23,800 Canadian and 296,980 American women were diagnosed with breast cancer in 2013 (American Cancer Society [ACS], 2013; Canadian Cancer Society [CCS], 2013). Of those, 4,284 Canadian and 64,560 American women were younger than 50 years (ACS, 2013; CCS, 2013). A diagnosis of breast cancer is imbued with a constellation of challenges as patients and their families face this life-altering event. Some patients experience psychological morbidities (Kissane et al., 2004; Strong et al., 2007; Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), cancer-related pain and fatigue (Fiorentino, Rissling, Lie, & Ancoli-Israel, 2011; Matthews, Schmiede, Cook, & Sousa, 2012), or practical problems such as navigating the cancer system (Carroll et al., 2010; Schwaderer & Itano, 2007). Cancer-related treatment complexities have initiated the development of organizational approaches toward streamlined systems of care. Despite efforts toward “re-engineering” healthcare systems, patients and their families continue to experience obstacles as they navigate the labyrinth of oncology care.

Person-centered care is an approach aimed at ameliorating the care experience for patients with cancer. The approach considers patient desires and goals, which then are woven into overall care plans that emphasize the importance of a partnership between care providers and patients (Fitch, Porter, & Page, 2008; Thomsen, Pedersen, Johansen, Jensen, & Zachariae, 2007). Hack et al. (2005) reported a significant increase in women’s desires to participate in their treatment plans, emphasizing the importance of education and partnership between healthcare professionals and patients.

A lack of coordination of oncology care often results in unnecessary delays of treatment (Dohan & Schrag, 2005), and exists for patients in rural and urban areas. In the rural domain, patients with breast cancer may experience additional challenges because of the increased travel costs, time, and limited access to supportive care services. Rural women with breast cancer also may undergo

**Purpose/Objectives:** To delineate the role of the oncology patient navigator, drawing from the experiences and descriptions of younger women with breast cancer.

**Research Approach:** Interpretive, descriptive, qualitative research design.

**Setting:** Participants’ homes, researcher’s home, and via telephone, all in Winnipeg, Manitoba, Canada.

**Participants:** 12 women aged 50 years or younger who were diagnosed with breast cancer within the last three years.

**Methodologic Approach:** Face-to-face semistructured interviews explored patient experiences with the cancer care system, including problems encountered, unmet needs, and opinions about the functions of the patient navigator role. The audio-recorded interviews were transcribed and data were broken down and inductively coded into four categories. Constant comparative techniques also were used during analysis.

**Findings:** The role of the oncology patient navigator included two facets: “Processual facets,” with the subthemes assigned to me at diagnosis, managing the connection, mapping the process, practical support, and quarterbacking my entire journey; and “Personal qualities: The essentials,” with the subthemes empathetic care tenor, knowing the cancer system, and understanding the medical side of breast cancer.

**Conclusions:** Despite the tremendous effort directed toward enhancing care for younger women undergoing treatment for breast cancer, gaps continue to exist. Younger women with breast cancer require a care approach providing ongoing dialogue, teaching, and emotional support from the point of diagnosis through treatment, including transitions of care within the oncology setting and back to their primary care practitioner.

**Interpretation:** Oncology nurse navigators are well positioned to provide patients with anticipatory guidance from diagnosis to the end of treatment.

**Key Words:** breast cancer, patient navigation, patient navigator, nurse navigator, supportive care

more invasive surgical approaches because of the lack of treatment resources available (Beaulieu, Massey, Tucker, Schoenberg, & Ross, 2003; Canadian Breast Cancer Network [CBCN], 2001). For example, women living in

rural areas are less apt to choose breast-conserving treatments than those living in urban centers (Beaulieu et al., 2003; CBCN, 2001; Meden, St. John-Larkin, Hermes, & Sommerschild, 2002). By choosing to undergo a mastectomy, women may eliminate the need for adjuvant radiation, which reduces the amount of travel time required for more treatment. That decision-making process may be difficult for patients and their families because it often occurs soon after their initial diagnosis.

Research has indicated that younger women with breast cancer also may face unique challenges, including the potential loss of fertility, early menopause (Adams et al., 2011; Coyne & Borbasi, 2006; Gould, Grassau, Manthorne, Gray, & Fitch, 2006; Thewes, Butow, Girgis, & Pendlebury, 2004), disruptions to 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). Younger women may feel isolated among the broader cancer population because of their stage of life or their age (Gould et al., 2006), and they may have a higher incidence of cancer-related post-traumatic stress disorder symptoms (Cordova, Studts, Hann, Jacobsen, & Andrykowski, 2000; Koopman et al., 2002). These studies highlight only some of the unique challenges a younger woman may face in addition to negotiating the complexities of the oncology care system.

An approach aimed at enhancing coordination of care in the oncology setting is the implementation of patient navigation programs (Ell, Vourlekis, Lee, & Xie, 2007; Melinyshyn & Wintonic, 2006; Psooy, Schreurer, Borgonkar, & Caines, 2004; Thorne, Bultz, & Baile, 2005). The original intent of patient navigation was to expedite diagnostic and treatment services while facilitating access to care for marginalized individuals (Freeman, Muth, & Kerner, 1995). As patient navigation programs have evolved, the role of the patient navigator remains context-specific and varied (Bowman & Grim, 2008; Fillion et al., 2012).

The role of an oncology patient navigator has been defined by Pedersen and Hack (2010) as

- (a) A trained individual who facilitates timely access to appropriate health care and resources for patients and their families, (b) a skilled communicator, who provides holistic care, empowering patients with education and knowledge about their illness, and (c) an individual who is knowledgeable of the cancer system (p. 59).

Definitions continue to remain varied; however, ongoing research toward the development of the professional navigator role is evident in the empirical literature (Amir, Scully, & Borrill, 2004; Bowman & Grim, 2008; Fillion et al., 2012). Breast cancer nurse navigators (NNs), for example, have been defined as nurses who initiate

contact with newly diagnosed patients to offer support, education, and information regarding their diagnosis (Doll et al., 2003; Ell et al., 2007; Fillion et al., 2006). Other definitions of patient navigators extend the navigator role through to the end of treatment (Carroll et al., 2010; Corporate Research Associates Inc., 2004). Therefore, prior to implementing a role aimed at ameliorating care for a specific population, patient perspectives concerning their experiences and needs must be understood. To date, a gap remains in the literature defining the oncology patient navigator role from the perspectives of younger women with breast cancer who have not received formal navigational support.

The current interpretive, descriptive study sought to explore and articulate an empirically based description of the role from the perspectives of younger women with breast cancer. The study was informed by the Supportive Care Framework, which uses the constructs of human needs, coping, and adaptation as a foundation for interpreting how patients and families experience and cope with cancer (Fitch et al., 2008). An interpretive, descriptive design was employed to capture the themes arising from participant perceptions as expressed in the face-to-face interviews.

## Methods

### Participants

Participants were included if they were diagnosed or treated for breast cancer within the last three years and were able to read and speak English. In addition, all participants were younger than 50 years. Efforts were made to capture the experiences and perspectives of rural and urban participants. The final sample was comprised of 12 participants (see Table 1).

### Procedures

The study was approved by the ethical review board for human subjects research at the University of Manitoba and CancerCare Manitoba's Research Resource Impact Committee. All participants provided informed, written consent to participate. Interviews were conducted during a 10-month time period.

Meetings were held with oncology nurses and social workers at CancerCare Manitoba, a regional outpatient cancer center located in Winnipeg, Manitoba, Canada, to introduce the study and request assistance with recruitment. The nurses and social workers were provided with a script to read to all eligible participants, informing them of the study. Participants then were provided with the researcher's contact information. Although 14 individuals expressed interest in participating, the final sample was comprised of 12 participants. One potential participant had family commitments and the other was overwhelmed with her treatment.

Most interviews were conducted face to face in the participants' homes. One interview was conducted via telephone because of the participant's remote, rural location, and two interviews took place in the researcher's home. All interviews commenced following an explanation of the study and the signing of the consent form. A short demographic form also was completed by the participants. Interviews ranged from 45 minutes to two hours in length. All participants granted the researcher permission to audio record the interviews. The interviews were transcribed verbatim and saved on a flash drive, which then was given to the researcher and saved on a password-protected computer hard drive and then deleted from the flash drive. To maintain confidentiality and anonymity, no identifying information appeared on any of the data collected for this study. All field notes and demographic data were identified by code numbers assigned to each participant, and all data were kept in a locked filing cabinet.

The interviews began with open-ended questions about participant breast cancer diagnoses, followed by questions regarding the challenges participants had faced during their cancer care trajectory. The researcher also asked direct questions concerning information availability, resources, and the concept of the patient navigator. Questions about the patient navigator role were asked during the midpoint of the interview, including, "Have you heard of patient navigation?" and "Would you use the services of a navigator?" The final closing questions were, "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?" Those questions provided an invitation for participants to share some lessons learned while cuing them that the interview was coming to a close.

## Data Analysis

The interpretive description of the patient navigator role was created by reviewing the transcripts thoroughly and repeatedly over time. 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 data analysis process (Thorne et al., 2005). Patton (2002) defined *triangulation* as a means to strengthen a study by using several kinds of methods or data. Triangulation strategies included a thorough analysis of the interviews, the reflexive journal notes, and a comparison of the findings with relevant empirical literature. The researcher strived for data saturation during this process, with the goal of finding and identifying all new events or pieces of information that supported the identified categories. When data saturation was

**Table 1. Participant Characteristics (N = 12)**

Characteristic	$\bar{X}$	SD	Range
Age (years)	43	4.5	36–49
Characteristic	n		
<b>Residence</b>			
Urban	8		
Rural	4		
<b>Marital status</b>			
Married or common law	10		
Divorced	1		
Separated	1		
<b>Treatment stage</b>			
First-line treatment <sup>a</sup>	6		
Survivorship	5		
Newly diagnosed	1		
<b>Number of children</b>			
Children aged 16 years or younger	7		
Children older than 16 years	2		
No children	3		

<sup>a</sup> Five undergoing chemotherapy and one undergoing radiation

reached, the data were further analyzed by iterative reading of the interview transcripts and conducting an in-depth analysis of the emerging theme categories and their interpretations.

## 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). In the current study, the researcher validated the study findings by using a variety of means to ensure accuracy. First, one of Canada's well-known patient navigation development managers reviewed the results of the study and commented on the congruency of the findings with previous studies. The data analysis and coding were discussed on an ongoing basis between the researcher and an experienced mentor to ensure the validity of the emerging framework and corresponding themes. The main categories, themes, and subthemes were submitted to an additional colleague for additional face validity. According to Patton (2002), the credibility of the researcher is important and adds an essential element to the study's rigor. The researcher has studied the developments in patient navigation for four years and published two peer-reviewed articles on patient navigation. The researcher also worked as a breast cancer educator, assisting patients and families along the breast cancer disease continuum.

The concept of dependability also was used to ensure rigor within the current research study. Dependability refers to how reliable the study results are and should be incorporated into the measures of rigor. One strategy

targeted toward ensuring dependability is referred to as triangulation. 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.

Results

The similarities emerging from the interviews fell within four categories that have a logical order. The categories, with corresponding themes and subthemes, are placed in temporal order in Table 2. The findings are illustrated in Figure 1.

Unmet Needs or Problems Encountered

Participants described a complex matrix of care influenced by a variety of contextual factors. In the beginning phase of the interview, the participants were asked whether they had experienced an unmet need during their treatment trajectory. Most participants offered a detailed account of an unmet need or problem they had encountered. However, two participants briefly described some obstacles they had experienced but did not consider to be problems or unmet needs. Four themes were identified, including (a) informational, (b) unanswered questions, (c) lack of emotional support, and (d) lack of coordinated care.

**Informational:** A diagnosis of cancer often elicits a response of anxiety and uncertainty in patients. All participants recounted their sense of shock on receiving the diagnosis. The participants described a variety of informational difficulties, including challenges associated with understanding information related to their diagnosis or treatment plan. One participant said,

He [the doctor] said I could do the lumpectomy. . . . If I did the lumpectomy, I would have to do the

chemo[therapy] 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[therapy] and then my radiation.

For younger women in particular, concerns were raised with regard to childcare, fertility, and working through cancer treatment while simultaneously balancing the demands of a young family. Some participants experienced informational gaps concerning their surgical procedures, pathology reports, and diagnostic time delays.

One participant described “missing information” in the context of making her surgical decision. She underwent extensive reconstructive surgery without knowing that her cancer had metastasized. News of her metastases was conveyed after her surgery. Regrettably, because of healing difficulties, her chemotherapy was further delayed.

**Unanswered questions:** Many participants recounted challenges to obtaining answers during their treatment trajectory. Their difficulties included not knowing what or who to ask and feeling rushed by their healthcare providers. Other participants commented on their inability to obtain clear answers to their questions. The following exemplar captures one participant’s experience during surgical decision making. She asked her doctor what he recommended for her.

He [the doctor] didn’t recommend anything . . . so I had to choose [between a lumpectomy and a mastectomy] and I had no idea where to go or what to do. . . . I started calling people who had gone through it . . . 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.

Table 2. Younger Women’s Experiences of the Breast Cancer Disease Trajectory and the Defining Attributes of the Oncology Patient Navigator

Unmet Needs or Problems Encountered	Emotional Reactions	Ways of Coping	Description of the Oncology Patient Navigator: Critical Attributes	
			Processual Facets	Personal Qualities: The Essentials
Informational need	Uncertainty Frustration	The relentless pursuit for answers	–	–
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	Avoidance	Mapping the process Practical support Quarterbacking my entire journey	Understanding the medical side of breast cancer



### Lack of emotional support:

Many participants felt a lack of emotional support from their healthcare providers and experienced delays in connecting with social workers, or attempted to enroll in support programs with waiting lists. A young mother described an inner turbulence related to uncertainty as she endured her treatments while working simultaneously. She spoke about her “episodes” of crying in her car and felt this was a “safe” place to release some emotions.

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?

Some participants highlighted the need for emotional support for themselves and their partners and children. One participant highlighted her own need for support.

Women can suffer from emotional difficulties during their treatment, there’s a lot of ups and downs . . . they have a little form that you fill out [at each chemotherapy appointment] and on there you rate it 1–10 and it does ask about emotions. . . . I rated myself usually at a 5 or lower. . . . they showed concern but never referred me anywhere.

**Lack of coordinated care:** Some participants encountered delays in their diagnosis and treatments, whereas others commented on the confusion surrounding their treatments.

About seven weeks after I had the mastectomy . . . I was calling the oncology desk . . . and the radiation oncology desk, I was trying to figure out what my next steps were and I couldn’t really get anybody. I

### The Oncology Patient Experience

- Unmet Needs or Problems Encountered**
- Informational
  - Unanswered questions
  - Lack of emotional support
  - Lack of coordinated care

*Emotional response to the unmet needs or problems encountered*

- Ways of Coping**
- The relentless pursuit for answers
  - Becoming the squeaky wheel
  - Avoidance

### Oncology Patient Navigator Role

- Processual Facets**
- Assigned to me at diagnosis
  - Managing the connection
  - Mapping the process
  - Practical support
  - Quarterbacking my entire journey

- Personal Qualities: The Essentials**
- Empathetic care tenor
  - Knowing the cancer system
  - Understanding the medical side of breast cancer

Diagnosis

Transition to primary care provider

**Figure 1. Aspects of the Oncology Patient Navigator Role Identified Through the Experiences of Younger Women With Breast Cancer**

kept getting a clerk who said, you know, “Someone will call you back,” and I didn’t know would they do chemo[therapy] first or radiation first or what’s gonna happen.

### Emotional Reactions to the Unmet Needs or Problems Encountered

As participants described their unmet needs or problems they encountered, some individuals also described their reactions to these adversities, whereas others conveyed feeling states or emotional responses through their body language, verbal tone, and storytelling. Four themes were generated under this category: (a) uncertainty and frustration, (b) anxiety, (c) powerlessness, and (d) vulnerability.

**Uncertainty and frustration:** Uncertainty and frustration penetrated the narratives of many participants as they described their confusion around whom to call and what to expect concerning treatment options and diagnostic tests. One participant’s frustration is captured in the following quote about her oncologist’s error regarding her treatment plan.

How long do you wait between ending of chemo[therapy] and beginning of radiation? And she [the oncologist] 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 yeah, you do need radiation.” And it’s like ah . . . I shouldn’t be the one having to tell you this.

**Anxiety:** Numerous participants described incidents of anxiety fueled by a constellation of events, including mistrust in the system, missing information, unanswered questions, and inconsistencies in care.

**Powerlessness:** The next theme, “powerlessness,” emerged from accounts of participants who expressed their attempts to gain control over their care. One participant recounted feeling disappointed by her doctor’s response to her partner’s question.

My partner asked, “Is there any consideration we should be giving to diet? . . . just as she goes into chemo[therapy].” And [the doctor] 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.

**Vulnerability:** Participants felt a sense of vulnerability at various stages of their disease trajectory, as captured in the following poignant exemplar of a participant at the end of treatment.

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 participant experienced acute reactions to her chemotherapy resulting in numerous hospitalizations, which eventually rendered her unable to complete her prescribed course of treatment. She described her sense of vulnerability.

My doctors and nurses never called to follow-up to see if I was having issues with my chemo[therapy] 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.

Emotional reactions to these unmet needs resulted in a myriad of responses. Their reactions triggered numerous ways of coping as they journeyed through the remaining stages of their breast cancer treatment.

## Ways of Coping

This category exemplifies 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: (a) the relentless pursuit for answers, (b) becoming the squeaky wheel, and (c) avoidance.

**The relentless pursuit for answers and becoming the squeaky wheel:** Many participants spent their days searching for answers to the plethora of questions and concerns that arose during their illness trajectory. Some participants felt they were on a never-ending quest. A participant and her spouse commented on their most profound challenge.

**Researcher:** What would you say has been your biggest challenge throughout your experience?

**Participant:** Just trying to get answers.

**Spouse:** 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 commented on excessive wait times and felt they needed to become the so-called squeaky wheel—the one who persists the most or the loudest and “gets the grease,” or, in this case, the answers. They relentlessly phoned their physician’s office, as this was their only option to have questions or concerns addressed.

**Avoidance:** Participants drew from a constellation of coping mechanisms fueled by their unmet needs or problems. 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 felt 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 participants avoided pursuing emotional support for their family members because of difficulties

finding information related to caregiver support and support group wait times.

## The Processual Facets

The oncology patient navigator role is explicated by two themes parsed from the narratives. The first theme, “the processual facets,” includes the most critical areas related to the process of navigating the oncology healthcare continuum where navigation could provide the most benefit. This theme highlights the importance of both the timing and duration of contact with the oncology patient navigator during the entire treatment trajectory process. Five subthemes emerged under this theme: (a) assigned to me at diagnosis, (b) managing the connection, (c) mapping the process, (d) practical support, and (e) quarterbacking my entire journey.

**Assigned to me at diagnosis:** The shock of the diagnosis and uncertainty surrounding the treatment process penetrated the participant transcripts. Having someone assigned to the participants was viewed as a pivotal aspect of the patient navigation role. The following participant exemplars describe the essence of this subtheme.

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

Another participant stated,

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.

One participant spoke about the need for someone to assist patients at the point of entry to the healthcare system.

There’s a weird thing that happens at the time that you get the diagnosis. . . . Anyone who’s in that room, you’re instantly connected with. . . . To me, if the patient navigator could be there then . . . 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.

**Managing the connection:** Participants emphasized that contact with the patient navigator should be more frequent during times of uncertainty, such as transitions in care or transferring back to their family physician following treatment. Communication preferences included email, telephone calls, and face-to-face

consultations between the patient navigator and the patient. Most participants felt that the navigator could periodically contact 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 emerged as communication obstacles. One participant stated,

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?”

Another participant captured her idea of an effective approach to connecting with the patient navigator.

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:** Participants described the importance of someone assisting them through the oncology treatment process. An abundance of challenges were woven into the participants’ responses in trying to understand and navigate their treatment trajectory.

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[therapy] 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.

**Practical support:** Participants felt that the oncology patient navigator could provide direction related to other aspects of care, including links to resources such as financial assistance, transportation tips, and child-care arrangements.

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

## For Further Exploration

This month’s Methods and Meanings feature highlights the current article as an example of how authors can best enhance their study’s credibility. Read more on page 89.

people sent me, what can we do about it and how do we explain to them [that] no, I'm not done [with] my chemo[therapy]?"

**Quarterbacking my entire journey:** The last subtheme emerged as many participants described the importance of having someone they could call who knew their story throughout their entire illness trajectory. Some participants spoke about the nurturing relationships with their chemotherapy nurses and the difficulty they felt when they transitioned out of their nurse's care.

I think it would be good to have that reinforcement of a person saying, you know, "This is what we offer" . . . 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 needed 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're accepting the fact that you don't have hair . . . I think if you follow the person through their treatment, you would find that they have different needs at different stages.

Another participant felt uncertain as to who was directing her care.

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? . . . You know, so there isn't anyone who kind of brings that together.

## Personal Qualities: The Essentials

Participants also reported their perspectives of the oncology patient navigator's essential personal qualities. The subthemes include: (a) empathetic care tenor, (b) knowing the cancer system, and (c) understanding the medical side of breast cancer.

**Empathetic care tenor:** Many individuals commented on the caring attitudes of nurses that fostered a feeling of safety. Participants recounted times when nurses listened to their needs and cultivated a sense of "presence" not evident in many other care providers. That type of caring experience possibly influenced the participants as they referred to the nursing profession as most suited to the patient navigator role.

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

**Knowing the cancer system:** Knowing the cancer system was important for many participants, emphasizing the need for patient navigators to be familiar with the cancer system and patient resources.

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.

Importantly, providing anticipatory guidance through the cancer care labyrinth was an essential aspect of the patient navigator role, as complexities exist throughout the entire treatment trajectory.

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.

## 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 treatment side effects, pathology reports, or various physical concerns they might be experiencing.

I chose a nurse [to fulfill the role] because of the medical background . . . 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.

Another participant stated,

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."

## Discussion

Patient navigator roles have been highlighted by healthcare professionals and described by patients who have previously experienced navigation during their cancer journey. An important aspect of patient navigation is removing obstacles or perceived barriers to care as defined in the literature (Freeman et al., 1995; Pedersen & Hack, 2010; Schwaderer & Itano, 2007). The participants in the current 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 time



of diagnosis. The current study did not explore the meanings associated with assigning a patient to an individual, but one may hypothesize that patients feel a sense of safety and security in knowing they have someone who is essentially assigned to their case.

Modes of communication such as email, telephone, and face-to-face consultations between the patient navigator and patient were favored by the participants. A pilot study conducted by Beaver, Twomey, Witham, Foy, and Luker (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 patients in the control arm. Telephone support interventions have been well documented in the literature as an acceptable approach to providing counseling and education (Badger, Segrin, Dorros, Meek, & Lopez, 2007; Beaver et al., 2006; Belkora et al., 2012; Leahy et al., 2013).

The participants in the current study spoke about feelings of “withdrawing” and “cocooning” during the treatment phase, which diminished their energy to reach out for assistance. Most participants would have welcomed the patient navigator contacting them periodically as opposed to sitting in silence, particularly during weekends or evenings. That sentiment was echoed in a weekend support telephone intervention study for women with breast cancer undergoing chemotherapy where patients were provided with a pretreatment informational and educational call (Smithies, Bettger-Hahn, Forchuk, & Brackstone, 2009). The women felt that hearing the information fostered their understanding of the numerous treatment-related side effects, as well as emergency contact information that may have been missed in previous appointments.

The empirical research concerning the original development and use of patient navigation programs was based on system fragmentation and individuals getting lost in the process (Corporate Research Associates Inc., 2004; Ell et al., 2007; Ferrante, Chen, & Kim, 2007; Psooy et al., 2004). Most participants in the current study felt lost or experienced difficulty navigating their own way through at least one phase of the breast cancer illness trajectory. The participants also emphasized the importance of “being heard” and “being understood” by the patient navigator. Therefore, conveying empathy is an essential personal aspect of the individual assuming the patient navigator role. Related to that finding, a patient navigation review article commented on an individual’s personality and the potential influence it may have on the efficacy of the program (Robinson-White, Conroy, Slavish, & Rosenzweig, 2010). In other words, the personality of the patient navigator may contribute to the success of the navigation program. With that in mind, the navigator should be an individual able to convey a genuine sense of empathy toward patients and families.

Ten of the 12 participants in the current study felt that the navigator should understand the medical aspects of breast cancer. Seemingly, this facet of the role negates the ability of a lay individual to assume the role of the oncology patient navigator. However, two participants in this study felt that the navigator did not need to convey medical information because their oncology nurses had been able to answer many questions for them. Regardless, the majority of study participants felt the navigator should be able to respond to the “medical side” of their questions; for two participants, a navigator telephone consultation could have prevented unnecessary hospital or clinic appointments. 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 and their side effects. Similarly, a study by Korber, Padula, Gray, and Powell (2011) found that patients felt the most important aspect of navigation included education related to their cancer and symptom management. As such, findings in the empirical patient navigation research indicate that NNs are becoming more popular in response to the level of education required to appropriately assess and assist patients through the cancer care trajectory (Corporate Research Associates Inc., 2004; Fillion et al., 2006; Lee et al., 2011).

The current study highlights perceived gaps in information and education, as well as ongoing uncoordinated patient care that may trigger a cascade of emotions for patients and their families, including distress, frustration, and anxiety. That may place unnecessary demands on emergency departments, nursing staff, and other support services. The participants in the current study placed many telephone calls to doctor offices, visited emergency departments, or, most unfortunately, sat in silence as they endured their treatments. Compared to older women who may face cancer with existing comorbidities (Yoo, Levine, Aviv, Ewing, & Au, 2010) and less social support (Ashida, Palmquist, Basen-Engquist, Singletary, & Koehly, 2009), the younger women in the current study identified concerns about fertility, child care, body image, and career disruptions. Understanding

## Knowledge Translation

Patients with cancer require an ongoing assessment of supportive needs throughout treatment.

At diagnosis, patients should receive an information package containing resources, links to support websites, and a map of their projected treatment trajectory.

On treatment completion, patients should receive written guidelines for their follow-up care.

the perspectives of these younger patients with breast cancer provides insight toward the development of the patient navigator role as one that provides anticipatory guidance and person-centered approaches to care.

## Limitations

The limitations of the current study include the possibility of retrospective bias or response shift. Five of the 12 patients had completed their treatments for breast cancer within the last three years. However, those 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 12 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 during a period of 10 months and, despite recruiting efforts from various sources and an expansion of the sampling frame, only 12 individuals participated in the study. Of those, nine had children; however, only six had children younger than age 16. Younger children are more dependent on their parents, which potentially increases the demands and responsibilities of patients enduring treatment for cancer.

The lack of rural participants was another limitation. Notwithstanding the assistance of the Community Cancer Program Network, which provides ongoing communication with the rural oncology treatment centers in the province, only four participants were enrolled from the rural domain. Compared to patients living within the city limits where resources and tertiary care centres often are easily accessed, rural patients' experiences may reveal increased difficulties with access to appropriate healthcare or limited resources. Additional research is required to explore the perspectives of the rural patient population with respect to the oncology patient navigator role.

## Implications for Nursing

NNs may need to schedule a mutually agreed upon telephone follow-up call with their patient during certain times of the illness trajectory. NNs should consider scheduling a time such as after surgery, after initial chemotherapy treatment or at the end of treatment for a call or face-to-face meeting. Oncology nurses need to recognize the difficulties their patients face when transitioning through all phases of care. Oncology nurses and NNs then can provide anticipatory guidance through enhanced communication and support, which may ease the multifaceted burden of the breast cancer trajectory. All nurses should understand the requirement for ongoing assessment of informational, educational, and emotional

support needs for their patients during all phases of the breast cancer illness trajectory.

The current study's findings also illustrate that NNs can assist patients with an information package containing relevant resources and links to support websites, as well as a comprehensive description of the patient's treatment trajectory. For example, NNs could provide patients with an estimated timeline for each treatment phase early in the trajectory. That could resemble a treatment map, which would act as a guide for estimating how long each treatment phase may take and what the patient should expect between certain phases. Such a tool may assist patients, who are either working or organizing active families, in making adjustments to their schedules and planning a targeted treatment completion date.

Oncology nurses and NNs also should refer their patients to other members of the healthcare team, including dietitians and pharmacists. Doing so may provide patients with an opportunity to learn and ask questions, which may cultivate a sense empowerment and control over certain aspects of their care.

Finally, oncology nurses and NNs must recognize that appropriate and relevant resources should be introduced and described to patients and family members during all phases of the breast cancer trajectory, including the completion of treatment. As indicated in the findings, the end of treatment can be a challenging time for patients. Oncology nurses and NNs are well positioned to ease this difficult time by providing patients with end-of-treatment education, written materials concerning follow-up care, and links to websites for emotional care information.

## Conclusion

Despite the small sample in the current exploratory study, the findings provide insight and guidance toward the expansion of current roles in oncology nursing and patient navigation. The study implies that, despite the tremendous effort and research directed toward advancing care for younger women with breast cancer, gaps continue to exist for some of these women. These findings can be used to provide direction for current patient navigation roles or, alternatively, to assist oncology centers as they develop their navigation programs.

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