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# An evaluation report of the nurse navigator services for the breast cancer support program

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## ABSTRACT

*The purpose of this quality improvement project was to evaluate the effectiveness of breast cancer care support provided by breast cancer care navigators (BCCN) for women attending the breast health clinic (BHC). This evaluative process examined patients' satisfaction with the nurse navigator program that focused on addressing breast cancer patients' informational needs, emotional support, and guidance through the cancer trajectory. A survey approach using Likert-type scales and open-ended questions was utilized to gather data. Patients seen at the BHC between July 2011 and July 2013 were sent the surveys by mail. The 154 responses constituted a 69% response rate. More than 90% of participants understood the information provided by the BCCN and were satisfied with the information that had been received. Psychosocial support from patient/family counselling services at the agency and in the community were among the most common request for resources. Recommendations include contacting patients directly after their initial meeting at the clinic and at least once after their treatments began, to ensure continuity and support. BCCN role was identified as being valuable with a positive effect on patients' experience.*

The nurse navigator role is expanding rapidly, as part of the health care team, due to changes in health care structuring and delivery. This change places a demand on oncology nurses to continue embracing opportunities and creating innovative strategies to ensure safe passage of patients along the entire cancer trajectory (Case, 2010). Studies identify that the presence of oncology nurse navigators has a measurable

outcome, and should be evaluated to examine the effectiveness and value of nursing interventions that optimize their specialized knowledge and skills for the benefit of patients' outcome (Case, 2010; Koh, Nelson & Cook, 2010). Evidence indicates that women who experience a breast cancer diagnosis and treatment describe the importance of health care provider roles in providing clear and consistent information for a supportive cancer journey (Grunfeld & Earle, 2010; Mayer, Gerstel, Leak & Smith, 2012; Singh-Carlson & Gotz, 2014).

The psychological impact of a cancer diagnosis can take many forms such as depression, anxiety, fear, and cognitive defects (Adler & Page, 2008). Evidence indicates that nurse navigators, who provide timely and appropriate information, ensure structure and continuity of care, thereby providing a psychologically supportive health care experience for patients (McMullen et al., 2013; National Coalition of Oncology Nurse Navigators, 2014; Winstead, 2012). Women report that the lack of a structured health care system that seamlessly connects all aspects of their cancer care from diagnosis to discharge increases anxiety and distress. Effectively addressing psychosocial impacts of cancer at diagnosis helps cancer patients develop coping skills, which can lead to a better treatment outcome and quality of life (Hryniuk, Simpson, McGowan & Carter, 2014; Institute of Medicine, 2008). Clinics have effectively designed and evaluated oncology nurse navigator programs that were organized to eliminate gaps in families' psychosocial, informational and care coordination needs for patients entering the cancer care centre (Horner, Ludman, McCorkle, Canfield, Flaherty et al., 2012; Koh, Nelson & Cook, 2010).

The concept of nurse navigator role is relatively new, with lessons that are starting to emerge regarding the importance of this role and its effectiveness for patient quality of life and care. Along with the growing introduction of this role in oncology care has come the use of several titles and functions for this role (Robinson-White, Conroy, Slavish & Rosenzweig, 2010). In addition to nurse navigator, the title 'patient navigator' has been used for 'oncology nurse navigator roles' that strive to streamline care and address current gaps in delivery. However, the patient navigator role has been filled by individuals from a variety of disciplines, including social workers, peer supporters, and lay individuals (Pederson & Hack, 2010). Pederson and Hack conducted a concept analysis of the patient navigator role and identified how this role helped to remove barriers to care, improve patient outcomes and enhance the overall quality of health care delivery. The breast health clinic in this study had identified an oncology nursing specialized role to care for breast cancer patients; therefore, the role was identified as the 'breast cancer care navigator' (BCCN).

The purpose of this project was to conduct an evaluation of the effectiveness of breast cancer care support that the breast

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cancer care navigator provides for women attending the breast health clinic. This evaluative process examined patients' perceptions of the nurse navigator program designed to address breast cancer patients' needs for information, emotional support, and guidance through the cancer trajectory. Results from this study helped to determine which innovative strategies helped to facilitate women's understanding and how the program could grow by integrating feedback into structuring of the BCCN practice and guidelines.

## BREAST HEALTH CLINIC

The breast health clinic (BHC) is located in one of British Columbia Cancer Agency's centres that is situated within a hospital setting. This created a great opportunity for a partnership to decrease time-related issues for clinical visits by providing diagnostic imaging and surgical management facilities.

Women who receive an abnormal mammogram at the screening mammography program of British Columbia, located in the hospital, are fast tracked and referred directly to the BHC. These women are typically seen within one week with a BHC mandate that a breast cancer diagnosis will be completed within 21 days of the first visit. Other BHC referrals are through family physicians, oncologists, surgeons, social workers, or self-referrals. During the BHC appointment, patients would see a general practitioner or surgeon for a clinical exam and for mammogram +/- ultrasound, if necessary. The goal is to schedule all appointments on the same day for patients' ease. Patients with biopsy-proven breast cancer would be referred to medical oncologists for neoadjuvant or adjuvant therapy. Unique to this breast health clinic is that a BCCN is available to provide additional support to breast cancer patients from the time of diagnosis. Approximately 90% of patients seen by the BCCN come through the BHC prior to a formal referral to a cancer centre.

The BCCN is present when the patient is initially informed about their breast cancer diagnosis. At this time, the patient receives an information kit consisting of *The Intelligent Patient's Guide to Breast Cancer*: a companion guide, booklets on exercise and nutrition, information on patient/family counselling support at the agency, as well as in the community, and information on post-treatment follow-up. The BCCN informs the patient about the next steps of cancer care and explains what the patient should expect in the cancer trajectory. The initial appointment ends with an invitation to patients to call or email the BCCN with any questions and an assurance they can call the BCCN at any point of the cancer care trajectory.

The BCCN is an experienced oncology nurse who is part of the interdisciplinary team and is knowledgeable about the standards, policy, and best-practice guidelines at BCCA. Data on the number of times breast cancer patients' contacted the BCCN indicated that 6,700 patients were seen since its opening in June 2011 to October 2013. These data from June 2011 opening date showed that the majority of patients had between one and four contact points with the BCCN. Data also indicated that the majority of contacts were made after diagnosis and prior to any treatments. A satisfaction questionnaire was created to survey patients' perceptions of care provided by BCCN and to explore how care could be improved.

## METHODOLOGY

Ethical approval was not required for this work because it was a quality improvement project with the aim of improving the quality of care. The feedback loop evaluation method fit this project given the quality improvement nature of this methodology (Gotz & Singh-Carlson, 2014). In the feedback loop evaluative method, recommendations from the findings are integrated into the program for best practice.

### Survey design

The breast research team, which serves the surrounding regional patient population, was inclusive of a medical oncologist, radiation oncologist, practising clinical nurses, nurse researchers, and nurse leaders. This team developed the evaluation survey based on the quality indicators of patient satisfaction with the BCCN role and breast cancer support. The survey was developed by evaluating other similar surveys in the literature and with discussions on length and the types of questions with the breast research team.

The survey consisted of a section for demographic information and a question about the number of times the patient had contact with the BCCN. Section two consisted of an evaluation of the care received using Likert-type response scales to rank the levels of satisfaction with care provided. Open-ended questions encouraged qualitative comments where participants could present other concerns that were not addressed in the previous survey questions. The questions focused on how patients perceived care; if their emotional and psychological feelings were addressed; if they felt prepared for their appointments; their comfort level when initiating contact with BCCN; and for participants to rate the care they received from BCCN.

After 47 surveys had been sent out and some participants had returned completed surveys, we recognized the need to adjust the items and add questions 9–10 in section 2. This adjustment was made because participants commented on their need to phone the BCCN for support between clinical appointments. A second question was focused on whether participants would recommend the BCH to other breast cancer patients.

### Data collection

Patients seen in the BHC between July 2011 and July 2013 were sent survey packages by regular mail. Inclusion criteria were: (a) cared for at the BHC by a BCCN; (b) approximately four months since the initial contact with BCCN; (c) completed or still undergoing treatments.

The survey package included an introduction letter, the survey, and a self-addressed return envelope. A program-specific identification number was assigned to each patient with the same number appearing on the mailing label and the self-addressed envelope. The letter of introduction provided an explanation about the purpose of the survey; anonymity of the survey; the voluntary nature of participation, and assurances their care would not be influenced whether or not they participated in the study. It also informed participants that completing and mailing the survey conveyed their consent. A reminder survey package was mailed out after three to four weeks to all those who may not have completed the first survey.

	<b>Responses</b>	<b>Percentage</b>
Characteristic		
English as a first language		
Yes	134	89.33
No	16	10.67
Need an interpreter		
Yes	16	12.12
No	116	87.88
Age		
< 64 years	79	52.67
> 65 years or over	71	47.33
Ethnicity		
Asian	10	6.90
European	46	31.72
North American	89	61.38
Level of education		
< High school	69	46.0
> High school	81	54.0
Live alone	27	17.89
Live with spouse/partners	122	80.79
Live with friends/others	2	1.32
Care for dependents		
Yes	40	26.85
No	109	73.15
Financial concerns/worries		
Yes	45	30.82
No	101	69.18
Number of times connected with BCCN		
1	32	21.62
2 - 4	71	47.97
5+	26	17.57
Not sure	19	12.84

### Data analysis

Survey data were entered into an Excel program file located on a password-protected computer. Hard copies of the surveys were stored in a locked file with only the research team having access to all the data to ensure confidentiality. Descriptive and inferential statistical analysis utilized SPSS statistical program for analysis. Variables were compared to explore statistical differences between and among responses so that the most effectual results could be identified and, thus, provide insight into the way care was provided. Content analysis was employed for qualitative data to identify themes within the data by coding and categorizing the comments.

## RESULTS

A total of 222 surveys were mailed out with 154 returned (69% response rate). It should be noted that only 175 participants received the adjusted surveys.

### Demographic data

Demographic data (see Table 1) are presented for two age groups (<64 and >65 years) and two education levels ( $\leq$ high school and >high school). Table 1 shows that 52.67% (n=79) of participants were below <64 years of age while 47.33% (n=71) were >65. Four did not indicate an age group. The majority (89.33%) (n=134) indicated English as their first language. While only 10.67% (n=16) indicated English was not their first language, 12.12% indicated needing an interpreter. This may indicate that although patients may speak English, they prefer an interpreter for medical visits to make it easier to understand and comprehend the medical language.

Ethnicity was grouped into similar populations served by the BHC. Caucasians were grouped as European 31.72% (n=46) [British Isles (n=17); European (n=29)] with North American 61.38% (n=89) [North American (n=86); French Canadian (n=3)]; and Asian 6.9% (n=10) [South Asian (n=2); East, West or South East Asian (n=7)].

Fifty-four per cent (n=81) had >high school education, 80.79% (n=122) lived with spouses/partners, and 26.85% (n=40) cared for dependents. More than half, 69.89% (n=101), indicated they did not have any financial concerns.

Data show that 47.97% (n=71) of the participants contacted the BCCN between two and four times with 17.57% (n=26) contacting BCCN more than five times. Interestingly, 21.62% (n=19) reported contacting the BCCN only one time; whereas 12.84% (n=19) were not sure about the number of contact points. This analysis was not able to identify the reason for the variation, but it is an interesting point to address in a future evaluation.

### Evaluation of BCCN role

Table 2 summarizes the responses to evaluating satisfaction with the BCCN role. Up to 10% of returned surveys were incomplete for this section of the survey with missing responses to one or more questions. This may be due to the fact that surveys were printed in a double-sided format and participants were not aware of this. These unanswered responses were included and identified as missing values. Response rate was calculated based on those who answered the specific question.

Data indicated most participants, 94% (n=135), understood the information provided by the BCCN with 85.2% (n=121) who reported being satisfied with the amount of information they received. Almost 90% (n=127) found the information 'mostly' useful. A high percentage 93% (n=142) felt mostly prepared for the next step in the care pathway. Most participants felt emotionally supported, 98% (n=136), and were comfortable, 95% (n=136), contacting the BCCN. The majority rated their care 'fair to excellent' (99%, n=141). For the added questions 9 and 10, of the 175 participants who responded, almost 98% (n=95) felt confident they would recommend this service to other breast cancer patients.

	<b>Responses</b>	<b>Percentage</b>
<b>Amount of information</b>		
Too much	4	2.84
A bit too much	7	4.96
Just right	121	85.82
A bit too little	6	4.25
Too little	3	2.13
<b>Useful information given by BCCN</b>		
Very useful	87	61.27
Fairly useful	40	28.17
Neutral	11	7.75
Fairly useless	11	.69
Entirely useless	1	2.12
<b>Understood information</b>		
Completely	80	55.94
Mostly	55	38.46
Somewhat	7	4.90
A little bit	1	.70
<b>Questions answered by BCCN</b>		
Completely	96	69.57
Mostly	35	25.36
Somewhat	4	2.90
A little bit	3	2.17
<b>Emotions addressed by BCCN</b>		
Completely	86	61.87
Mostly	30	21.58
Somewhat	20	14.39
A little bit	2	1.44
Not at all	1	.72
<b>Feeling prepped for next step</b>		
Completely	81	57.04
Mostly	37	26.05
Somewhat	14	9.86
A little bit	7	4.93
Not at all	3	2.12
<b>Comfortable to contact BCCN</b>		
Completely	112	78.32
Mostly	15	10.49
Somewhat	9	6.29
A little bit	5	3.49
Not at all	2	1.41
<b>Rate care from BCCN</b>		
Excellent	88	61.53
Very good	46	32.17
Fair	7	4.90
Somewhat poor	0	0
Very poor	2	1.40
<b>Aware can call BCCN for support</b>		
Yes	83	85.57
No	7	7.22
Was not sure	6	6.18
Prefer BCCN contact me	1	1.03
<b>Recommend care to others</b>		
Completely	82	84.54
Mostly	8	8.25
Somewhat	5	5.15
A little bit	1	1.03
Not at all	1	1.03

Eighty-six per cent (n=83) were aware they could call the BCCN for support with only seven who were not aware and six who were not certain they could call in at any time. One respondent would have preferred that the BCCN call them directly.

Most (98%) of the participants felt that psychosocial needs were addressed by the BCCN. Statistical analysis for education, dependents, and finances did not show any statistical differences between groups when compared with questions on care provided by BCCN.

### Themes from the qualitative data

Only 32% (n=46) of the participants responded to the first qualitative question (What other information/services would you have liked to receive?) and 52% (n=73) responded to the second (Is there anything else you would like to share with us about your experience?). Psychosocial support from the agency's patient and family counselling service and from the community were among the most common informational need requests. Specific comments relating to the BCCN services were informative for improvements and are presented in Table 3.

Three themes—Contacting the BCCN; Supportive Needs; and Informational Needs—emerged from participants' responses to the qualitative questions. Contacting the BCCN included comments on how the BCCN herself could have contacted patients upon completion of treatments. Participants mentioned how this would have relieved anxiety after discharge and during follow-up care. Comments on supportive needs included wanting patient and family care services at the agency and in the community for psychological and emotional support. Other comments shared were: too much information was given, which caused anxiety while waiting for test results; whereas another felt much of the stress and confusion was relieved by having someone available to help navigate the system. Comments regarding patients' needs for information included topics of breast cancer prevention and alternative treatments, port-a-cath info, lymphedema, skin care post-surgery and radiation.

## DISCUSSION

The BCCN program at the BHC strives to provide appropriate information, education, and emotional support for patients who are newly diagnosed, undergoing treatments or engaged in follow-up care. Its objective is to support family members and to serve as a liaison between the patient and their treatment providers. Its other objective is, with the BCCNs' guidance and assistance, to provide timely delivery of diagnostic, treatment, and follow-up services. It is anticipated these are key components of successful recovery. Evaluation of the BHC identified the value of the BCCN role and its effectiveness in helping the patients understand the cancer trajectory and fulfill informational needs.

The results from this evaluation support the importance of an interdisciplinary team approach with the BCCN role being integrated at the time of diagnosis and at different points along the cancer pathway. Evaluation of this model of care has shown how the BHC helped to decrease barriers by providing guidance; providing information to allow patients to make informed decisions, and providing psychosocial support that can reduce anxiety.

A systematic review of patient navigation in breast cancer reveals that navigation across many aspects of the breast cancer

Table 3: Verbatim quote examples		
Contacting the BCCN	Supportive Needs	Informational Needs
<p>Could have contacted us [patient] at different points in time in the steps of care, to see how they [patient] were doing.</p> <p>I would have appreciated a phone call or so right after getting home. I was told that she should have attended my appointments with me, but that never happened.</p> <p>I did attempt phoning her, but she was not there or the phone system was not working.</p> <p>Quite frankly, I had forgotten I could utilize this service after a couple of months, but the time I did phone and was given info was very helpful and promptly dealt with.</p> <p>Perhaps a little more contact in the beginning—i.e., use counselling service psychiatrist.</p> <p>I only needed to call about 3–4 times, but knowing I could call really helped.</p> <p>Perhaps a little more contact in the beginning by the BCCN, a phone call maybe.</p>	<p>The experience was made easier by having someone to talk with.</p> <p>Having a cancer buddy really helped every step of the journey.</p> <p>When talking about sentinel lymph node biopsy it would be good if they knew what it involves exactly.</p> <p>More information about what services are available from [XX]</p> <p>The truth about minimal differences on a woman's health by invasive protocols that were recommended would have been good.</p> <p>More time for discussion regarding side effects of after treatment (pills) for a person my age, 82 years old, to weigh out plusses would be good.</p> <p>I am still wondering about her role in the whole thing.</p> <p>It would have been helpful to have seen a bad radiation burn so I could have been more prepared.</p> <p>She is caring, knowledgeable and passionate about her work. She answered all my questions in a timely manner.</p>	<p>[Nurse] was kind enough to listen to me, as I made my decisions concerning surgery, with patience, humour and gentle guidance, which I truly appreciated.</p> <p>Overall, my experience was very positive. After talking with other patients from other parts of the lower mainland and the way they are sent from hospital to hospital for one procedure after another I feel very fortunate to have had all the great staff at ACC, as well as all my treatments.</p> <p>Social worker or counsellor should be offered at appointment, especially for financial aid.</p>

disease trajectory improves breast cancer care (Robinson-White, Conroy, Slavish & Rosenzweig, 2010). Evaluative studies have contributed to the feedback used to strengthen the nurse navigator program models of care delivery (Horner, Ludman, McCorkle, Canfield, Flaherty et al., 2012). Outcome data from these studies confirmed the nursing practice competencies and the value of the nurse navigator model (Case, 2010).

The competencies of the BCCN role can be compared to those outlined for the oncology nurse navigator by the Oncology Nursing Society (ONS) (Oncology Nursing Society, 2015). ONS identifies the following competencies for the oncology nurse navigator role: (a) demonstrating the professional role through continuing education with respective interactions with community and teamwork; (b) providing patients and families appropriate and timely education so patients can make informed decisions; (c) coordinate care within and across systems to promote optimum outcomes for patients; and (d) demonstration of interpersonal communication skills to advocate for patients by engaging patients and colleagues and utilizing written, spoken, and listening skills that promote patient-centred care (Brown et al., 2012; McMullen, 2013; National Coalition of Oncology Nurse Navigators, 2014). This evaluation of BCCN role at the BHC highlights the similarities between these two nurse navigator roles with equivalent competencies identified in both.

The Canadian Association of Nurses in Oncology has not identified the oncology nurse navigator as a specialized role. However, the certified specialized oncology nurse has navigation functions embedded in practice whether caring for patients in specialist centres or cancer patients as a specialized population in hospitals or communities (CANO, 2015). The BCCN has

a key role to play in the cancer care pathway. This is evidenced by results indicating respondents were generally satisfied with the care provided, the amount of information provided, and the guidance provided in navigating the health care system. This is a meaningful evaluation of the BHC, its organizational structuring, and the format of delivery, that addresses the patient population's needs leading to patient-centred care (Brown et al., 2012; Campbell, Craig, Eggert & Bailey-Dorton, 2010).

Other studies confirm that patients who received nurse navigation services responded positively to satisfaction surveys indicating that nurse navigator roles decreased barriers to care while increasing patient satisfaction (Hryniuk, Simpson, McGowan & Carter, 2014). Fillion et al. (2012), in the Canadian cancer setting, identified 'facilitating continuity of care' and 'promoting patient and family empowerment' as the dimensions of the professional navigation role. Furthermore, by providing effective patient education, informational needs, and psychosocial support through clear and consistent communication skill, the nurse in a BCCN role can be an active partner in engaging the patient in cancer self-management. The coordination of care from the time of diagnosis is vitally important since this leads to a good quality of life for women through all the stages of cancer care—screening and diagnosis to treatment and survivorship.

## RECOMMENDATIONS AND IMPLICATIONS FOR NURSING PRACTICE

Based on these quality improvement data, the BHC changed the protocol so that the BCCN is able to make direct contact with patients and ensure there are not any issues or concerns

that have arisen from the diagnosis, treatment or follow-up care. This need for patients to receive a call directly from clinical support nurses resonates with research where breast cancer patients, as mentees in peer mentor relationships, appreciated the call directly from the peer mentor because they lacked the confidence to make the call themselves (Singh-Carlson & Gotz, 2014). Furthermore, the BCCN contacts all the patients a day or more before their new patient appointment at the agency, and follows up with them on the same day as the new patient visit (or shortly thereafter) to ensure continuity and support and as a “check in” to answer any questions. Connecting with the patient at the time of discharge from the centre to the community would also reduce separation anxiety. Patients are well supported by the interdisciplinary oncology team during treatments, but may need supportive care, information on side effects and community resources after discharge.

Future recommendations for the BCCN would be to take the opportunity at every patient contact point to discuss symptom management, side effects of treatments, what patients should expect to feel and how to be in the patient role, information on resources, and follow-up recommendations. Evidence indicates that patients are normally overwhelmed and may not always hear everything that is said during the medical appointment; hearing it more than once can create space for understanding and retaining the information on diagnosis and treatment-related information.

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