A Specialist Breast Care Nurse Role for Women With Metastatic Breast Cancer: Enhancing Supportive Care

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Although improvements have been made in outcomes for women with early-stage breast cancer, as many as one third of women will develop and, subsequently, die from metastatic breast cancer. Although the prognosis for metastatic breast cancer generally is poor, median survival time from diagnosis of secondary disease is about three years; therefore, survival is highly variable (Johnston, 2010). Some women have rapidly progressive disease, whereas others can live with metastatic disease for as many as 10–15 years (Johnston & Swanton, 2006). A diagnosis of metastatic breast cancer has a profound emotional impact (Beacham, Hill, McDermott, O'Brien, & Turner, 2005), with the majority of women considering the recurrence more distressing than the original diagnosis (Warren, 2010). Some of these women experience clinically significant levels of distress (Caplette-Gingras & Savard, 2008; Turner, Kelly, Swanson, Allison, & Wetzig, 2005).

A wide variety of treatment options are available, including hormone therapy, chemotherapy, and new targeted therapies. These therapies are improving tumor response rates and, potentially, the survival of women with metastatic breast cancer (Geyer, Forster, & Lindquist, 2006; Miller, Wang, & Gralow, 2005). The care of women with metastatic disease usually involves a multidisciplinary team (MDT) of healthcare professionals, including medical and radiation oncologists, breast care nurses (BCNs), and palliative care specialists (Amir, Scully, & Borrill, 2004). Although the objective of the MDT is to provide optimal patient care, treatment and care may be fragmented.

Women diagnosed with metastatic breast cancer have unique and pressing psychosocial needs that differ substantially from the needs of women diagnosed with early breast cancer (Johnston, 2010). Issues confronting this patient group include living with uncertainty, dealing with the emotional impact of a life-threatening diagnosis, experiencing a sense of loss of control, and grappling with existential distress (Sarenmalm, Thoren-Jonsson, Gaston-Johansson, & Ohlen, 2009; Warren, 2010).

The Specialist Breast Care Nurse Role

The specialist breast care nurse has training and expertise in the management, treatment, and follow-up of patients diagnosed with breast cancer (Liebert, Parle, White, & Rodgers, 2001). He or she is an important member of the multidisciplinary breast care team, providing a range of key interventions (e.g., psychosocial support, information, patient advocacy, acting as liaison among the various members of the healthcare team) (Amir et al., 2004; Cruickshank, Kennedy, Lockhart, Dosser, & Dallas, 2008). Patients diagnosed with primary breast cancer benefit from access to a specialist BCN in terms of receiving continuity of support (Halkett, Arbon, Scutter, & Borg, 2006) and information about treatment options and side effects as well as clinical trials (Campbell, Khan, Rankin, Williams, & Redman, 2006). Women with metastatic breast cancer, however, report that the information and support provided to them is inadequate compared to the services available to them at their primary diagnosis (Johnston, 2010). In an Australian study of 842 women seen by four breast cancer nurses, only 7% of the participants were women with advanced breast cancer, although this group of women represented 35% of breast cancer cases in the hospital where the study was conducted (Aranda, Milne, & Osmond, 2002). BCNs also report that they often feel underresourced and ill-equipped to provide supportive care to patients with metastatic disease (Reed, Scanlon, & Felon, 2010). The Secondary Breast Cancer Taskforce established in the United Kingdom in 2006 identified a significant discrepancy between the level of supportive care received during women's treatment for primary breast cancer and

- Establish strong referral pathways from the physician to the breast care nurse to ensure that all women diagnosed with metastatic breast cancer have access to the service.
- Routinely elicit women's needs for information and support and the extent to which these are being met.
- Offer tailored information to women individually. This information may include resources on sexuality, lymphedema management, communication with children and family, clinical trials, treatment regimens, emotional coping, and complementary therapies.
- Refer patients to other services as needed, including psychology and social work, as well as physiotherapy and other support services.
- Be present as a patient advocate and provide contact with the medical team and other health professionals as required.
- Maintain a constant presence, providing continuity of care for the patient.

Figure 1. Key Objectives of the Metastatic Breast Care Nurse Role

Note. Based on information from National Breast Cancer Centre, 2000, 2005.

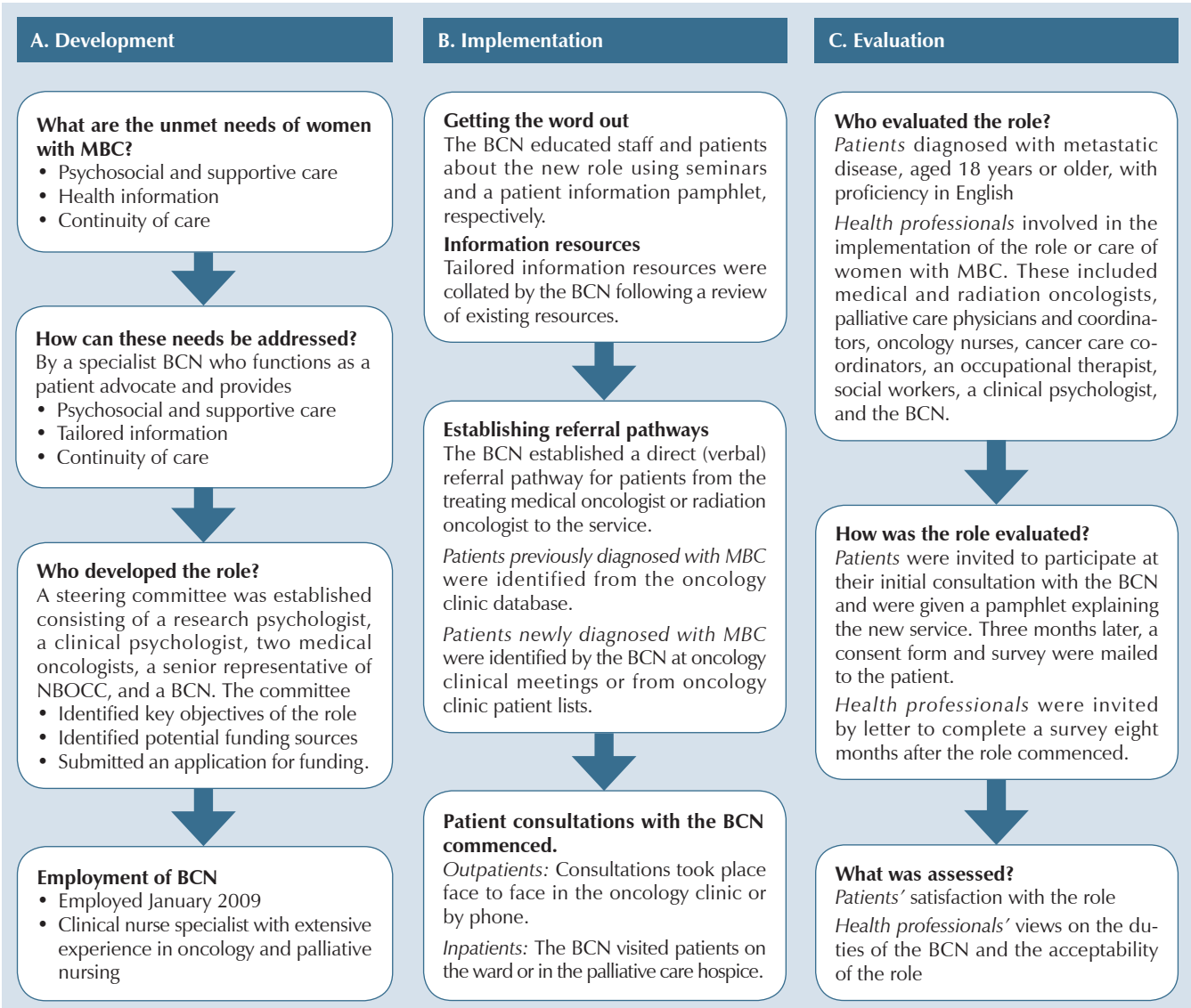
that received after a diagnosis of secondary breast cancer. One of the taskforce's key recommendations was that, in every breast care team, a dedicated clinical nurse specialist who has the skills and knowledge to manage metastatic breast cancer should be present (Breast Cancer Care, 2008).

In view of the demonstrated high levels of unique, unmet needs of women with metastatic breast cancer, the authors of the current article aimed to address this significant gap in service provision in Australia by developing and implementing a new specialist BCN model for these women. This article reports on the development and evaluation of the specialist metastatic BCN role in a large public teaching hospital located in Sydney, Australia.

The Role of the Metastatic Breast Care Nurse

Development and implementation: The setting for the development and implementation of the role was the Prince of Wales Cancer Centre, located at Prince of Wales Hospital, a 440-bed major teaching hospital in New South Wales, Australia. The new role was modeled on previous BCN roles designed for women with early breast cancer, but with features tailored to women with metastatic disease. Funding was available for a part-time role (24 hours per week). The key objectives of the new metastatic BCN role are presented in Figure 1. The service was successfully implemented, primarily by the new metastatic BCN, who worked closely with the multidisciplinary breast care team to establish the role. The processes involved in the development and implementation of the metastatic BCN role are summarized in parts A and B of Figure 2.

Evaluation: The new metastatic BCN role was evaluated to ensure that it met the needs of the target patient group and that it was perceived as acceptable by referring healthcare providers. A process (rather than impact) evaluation was adopted. Therefore, patient outcomes, such as quality of life and psychological distress, were not assessed. The duration of the evaluation was one year (May 2009 to May 2010). Existing survey instruments were adapted for the evaluation and separate self-report surveys were compiled from patients and health professionals (National Breast Cancer Centre, 2005).



BCN—breast care nurse; MBC—metastatic breast cancer; NBOCC—National Breast and Ovarian Cancer Centre

Figure 2. The Processes in the Development, Implementation, and Evaluation of the Metastatic BCN Role

The process involved in the evaluation of the new role is displayed in part C of Figure 2. Patients were asked to provide their views about the new metastatic BCN service using three-, four-, or six-point Likert-type rating scales. The proportion of patients who endorsed items regarding satisfaction with various elements of the supportive care provided by the metastatic BCN is shown in Table 1. Forty-nine women provided preliminary verbal consent to participate in the evaluation, with five patients dying prior to the mailing of the survey. Thirty-one completed surveys were returned (response rate of 70%). The mean age of patients who took part in the evaluation was 54.2 years (range = 30–75 years). Most women were married or cohabiting (67%), had children (71%), spoke English at home (90%), and had lived with metastatic breast cancer for less than three years (71%). Twenty-three health professionals were invited to participate; 17 returned completed surveys (response rate of 74%). Results for health professionals are shown in Table 2.

Table 1. Patient Evaluation Regarding Perceived Satisfaction With Aspects of the Metastatic Breast Care Nurse Service

Description	n	Reported "Not Applicable" n
Timing and frequency of consultations		
Were satisfied with the length of consultations	25	2
Reported their first consultation with the breast care nurse was appropriately timed	24	4
Were satisfied with the number of consultations	23	1
Saw or spoke to the breast care nurse at time of their diagnosis of metastatic breast cancer	15	1
Emotional, practical, and spiritual support		
Were satisfied with the level of emotional support offered by the breast care nurse service	20	9
Reported the support experienced during consultations with the breast care nurse helped them to cope or feel better	20	9
Were satisfied with the practical support provided by the breast care nurse service	15	16
Had the opportunity to talk with the breast care nurse about spiritual issues	7	20
Coordination of care		
My supportive care and medical care were well coordinated within the multidisciplinary treatment team.	18	9
The breast care nurse communicated with other health professionals on my behalf, when required.	17	13
I was kept informed about all aspects of my treatment and supportive care.	17	11
Information and referrals		
Were satisfied with the amount of information provided	23	4
Were able to discuss their information and supportive care needs openly with the breast care nurse	23	7
Found the information resources provided useful	23	6
Were provided with referrals to other health professionals or services as required	15	15
Satisfaction with supportive care strategies		
Reported the supportive care received through the breast care nurse was "somewhat" or "very" important to them	26	4
Reported the service had made "some" to a "major" contribution to their care and well-being	25	3
Were satisfied with the overall care received from the breast care nurse	23	5
Suggestions for improving the role		
Provide a support group for women with metastatic breast cancer.	1	–
Include "project management" of metastatic patients' treatment into the role to facilitate streamlined passage through treatment.	1	–
Ensure support from the metastatic breast cancer nurse is available at diagnosis of metastatic disease, rather than later on.	3	–

N = 31

Discussion

The project evaluation demonstrates that the new metastatic BCN role was successfully implemented and is highly valued by the target patients and by healthcare providers. The majority of patients were satisfied with the overall supportive care provided by the metastatic BCN and perceived that the service had contributed to their care and well-being. Most women who perceived the emotional support provided by the metastatic BCN as personally relevant were satisfied with the level of support provided and perceived that it helped them to cope. All health professionals agreed that the metastatic BCN role had improved the provision and organization of supportive care for metastatic patients in the hospital. Some patients did not view the practical support, coordination of care, and spiritual support offered by the metastatic BCN service as applicable to them. That pattern parallels the view of health professionals that the main duties of the metastatic BCN are the provision of emotional support and information resources (ahead of coordination of care, clinical liaison, and provision of referrals).

The substantial proportion of women who responded "not applicable" to several elements of the metastatic BCN role may reflect the existence of several types of women diagnosed with metastatic breast cancer. Some patients have low levels of unmet needs, therefore requiring little formal support. Other women with metastatic breast cancer, however, have high levels of unmet need in the psychological, health information, and daily living domains (Aranda et al., 2005), with some experiencing high levels of psychological distress as well (Turner et al., 2005). This also was a new role; therefore, patients who had been living with metastatic breast cancer for several years and who did not have access to formal supportive care from a metastatic BCN at diagnosis were likely to be accustomed to dealing with their disease largely independently. Despite that, several of those patients stated that they would have liked the support of a metastatic BCN at the time of their diagnosis. The range of responses flags

Table 2. Health Professional Evaluation Regarding the Perceived Duties of the Breast Care Nurse and the Acceptability of the New Service

Description	n
Duties of the breast care nurse	
Provision of emotional support	14
Provision of information and education	14
Coordination of patient care	9
Facilitation of communication within the multidisciplinary team and clinical liaison	5
Arranging referrals to allied health professionals or other services	4
Referral pathways and information resources	
Reported the current referral pathways are effective. Several health professionals suggested the pathways could be expanded so that all members of the multidisciplinary team can refer patients to the metastatic breast care nurse.	10
Viewed the resources available to women with metastatic breast cancer, through the breast care nurse, as appropriate. Forty-seven percent of health professionals were not aware of the resources offered.	8
Acceptability and success of the metastatic breast care nurse service	
Agreed that the new role had enhanced • A multidisciplinary approach to metastatic breast cancer care • The availability of quality, tailored information for women with metastatic breast cancer • Continuity of care for this patient group.	17
Perceived that the new metastatic breast care nurse role was successful. The most successful aspects of the role included • Provision of specialized supportive care and follow-up to patients with metastatic breast cancer • Improved multidisciplinary care of these patients, particularly facilitation of communication within the multidisciplinary team • Improved continuity and coordination of patient care.	16
Suggestions for improvement of the role	
Convert the role from part-time to full-time.	6
Expand referral pathways to the metastatic breast care nurse.	3
Provide the metastatic breast care nurse with access to formal training in patient counseling (identified by the metastatic breast care nurse as a training need).	1
Provide a support group for women with metastatic breast cancer (identified by the metastatic breast care nurse as a need).	1

N = 17

the importance of the metastatic BCN regularly monitoring the information and supportive care needs of individual patients with metastatic breast cancer and routinely screening for distress (National Comprehensive Cancer Network, 2011).

Health professionals reported that the most successful elements of the role were the provision of specialized supportive care and follow-up, as well as improved multidisciplinary care for patients with metastatic breast cancer. The evaluation identified several aspects of the role that could be improved. Referral pathways need to be expanded so that allied health professionals, as well as medical and radiation oncologists, can refer patients to the service. The expansion of the role to a full-time position (which has since been achieved) will provide all patients with the opportunity to access the dedicated metastatic BCN around the time of their diagnosis of metastatic disease. In addition, identifying and meeting the professional development and training needs of the metastatic BCN are critical to facilitate performance in the role and to combat the possibility of burnout. The favorable attitudes of health professionals and patients toward the new service highlight the integral role that the specialist metastatic BCN has in the MDT, and the importance of the metastatic BCN as a source of information and psychosocial support for the patient.

The authors acknowledge that similar nurse navigator roles already exist in cancer care settings in the United States. The patient navigator role is designed to provide individualized assistance to patients, families, and caregivers to help them navigate the complex healthcare system at various points along the cancer trajectory (Wilcox & Bruce, 2010). The current role, however, may serve as a model for the implementation of the role in countries where a similar gap in service provision has been identified.

Conclusions

Strong support was noted from both patients and health professionals for the continuation and expansion of the service to meet the unique supportive care needs of patients with metastatic breast cancer. In view of the significant psychological impact of metastatic breast cancer, and the well-documented unmet needs of patients with metastatic disease, the new metastatic BCN role provides the opportunity to tailor treatment and supportive care to the needs of the individual patient and addresses a significant gap in service provision for this specific patient group.

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