Australian women's perceptions of a specialist breast nurse model

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Abstract

The aim of this study was to evaluate Australian women's perceptions of the specialist breast nurse (SBN) model developed by the National Breast Cancer Centre. Two hundred and forty women evaluated the care they received from a SBN. The SBN was perceived as a valuable link between women and the multi-disciplinary team, with continuity of care being rated as a major benefit. Over 80% of women reported the SBN to be effective in providing information and emotional support. There is a need to consider the establishment of SBN positions in treatment centres for breast cancer in Australia.

Introduction

In Australia, breast cancer is the most commonly diagnosed cancer and the leading cause of death from cancer in women (AIHW, 1998). Despite the fact that more women are diagnosed with breast cancer every year (AIHW, 1998), there is evidence that many women do not have adequate information about their disease and treatment, nor receive enough practical and emotional support from health professionals (Girgis et al, 2000). Specialist breast nurse (SBN) positions were developed in the United Kingdom as one strategy to improve the psychological wellbeing of women with breast cancer (Jary, 1996). Although randomised controlled trials (RCTs) have demonstrated benefits of SBN positions overseas (Watson et al, 1988; McArdle et al, 1996), the SBN role is less well developed in Australia.

The National Breast Cancer Centre (NBCC) developed a clinical pathway for SBNs, based on established SBN models from overseas (Maguire et al, 1980; Wilkinson et al, 1988) and evidence based guidelines for Australian clinical practice (NHMRC, 1995; NHMRC, 2000). The SBN intervention aims to increase the amount of information and psychosocial support women and their families are offered during treatment for breast cancer. A recent article has reported on the core findings from the implementation of the SBN intervention (NBCC, 2003). Evaluation of the SBN model by members of the treatment team is reported elsewhere (NBCC, 2000a). The present study reports on the women's perceptions of the SBN model.

Method

Seven treatment centres were selected to participate as a result of a competitive bidding process; these centres were spread across Australia and included rural and urban, private and public health care settings. The intervention consisted of five predetermined consultations with a SBN for eligible women at key treatment phases. Details of the SBN intervention are described elsewhere (Liebert et al, 2001). Seven senior grade nurses were trained to deliver the SBN model of care and received supervision during the project.

Women were eligible to participate if they had a diagnosis of breast cancer and were to be treated surgically; were aged over 18 years; and spoke and read English sufficiently to be able to complete the questionnaires. Eligible women who presented at any one of the seven centres between March and September 1998 were invited to participate if they were seen by the SBN after diagnosis, or pre-operatively and post-operatively whilst still an in-patient; and had received at least one of the following - chemotherapy or radiotherapy or follow up. Women completed a self-administered questionnaire at 2 and 6 months post diagnosis. The 2-month questionnaire assessed the women's perceptions of their consultations with the SBN during the time of diagnosis, treatment decision-making and surgery. The 6-month questionnaire explored women's perception of the care received from the SBN during the period of adjuvant therapy, and the overall care provided by the SBN.

Results

Of the 272 women who were eligible to participate, 240 (88%) women consented to participate; 217 (80%) completed the 2 month questionnaire and 209 (77%) completed the 6 month questionnaire. Demographic items were elicited from patient logs completed by the SBNs. Figure 1 shows the demographic profile of women who completed the 2 month questionnaire. No significant differences were found between women who completed the 2 month and 6 month questionnaire when compared with non-responders.

Figure 1: Demographic profile of women who completed the 2 month questionnaire

Characteristics	Respondents (n=217)
Age	n=216 (%)
18-29	3 (1.4)
30-49	65 (30)
50-69	106 (48.8)
70+	42 (19.4)
Marital status	*n=213 (%)*
Single	22 (10.3)
Married/de facto	133 (14.1)
Separated/divorced	25 (11.7)
Widowed	33 (15.5)
Education	*n=198 (%)*
Below School Certificate	87 (43.9)
School Certificate	34 (17.1)
Higher School Certificate	26 (13.1)
Technical College	22 (11.1)
University/College of Advanced Education	29 (14.6)

The SBN as a link between a woman and her treatment team

The majority of women reported that the SBN provided them with enough help in coordinating their care with the treatment team (Figure 2). Continuity of care was rated as a major benefit by 88% of women, and 97% of women reported that they benefited from the ongoing contact with the SBN. The SBN was viewed as a good communicator (98%), and skilled in conveying the woman's needs to doctors in the treatment team (96%). However, 15% of women felt their needs were not communicated to their general practitioner or other health workers.

Figure 2: Perceptions of the SBN at coordinating care

	n	%	n	(%)	n	(%)	n	(%)
Did the SBN provide you with enough help in the following:	**Much help as needed**		**Liked more support**		**Liked less support**		**Did not need help**	
	n	(%)	n	(%)	n	(%)	n	(%)
Understanding who treatment team was	62	(88)	5	(3)	0	(0)	17	(9)
Making sure doctors knew what was happening	156	(80)	8	(4)	1	(1)	30	(15)
Introduction to treatment team	143	(75)	9	(5)	0	(0)	39	(20)

Information about treatment, support networks and practical issues

The SBN was rated as having provided the right amount of information on most treatment issues and on support networks. The main areas that women reported they would have liked more information about were radiotherapy (12%), results of surgery (10%), breast reconstruction (10%), discharge and treatment planning (10%) and practical support (10%). The SBN offered all women printed resources about breast cancer. Forty-five percent of women were given written information related to their own diagnosis and treatment, and 73% had some of their consultations with the SBN taped. Sixty percent of those women found the tapes helpful.

Support for emotional, cultural and spiritual needs

Most women were satisfied with the emotional support offered by the SBN pre-operatively and post-operatively (98%), however 12% would have preferred more emotional support during adjuvant therapy. Eighty-two percent of women reported that their family and/or friends required information about their illness and 76% needed the opportunity to discuss their feelings and ask questions. Most women (94%) were satisfied with the emotional support provided to their family and friends by the SBN. About two-thirds of women (64%) reported that they were offered resources specific to their culture and 59% stated that they were given the opportunity to talk with a woman from their own culture or one who spoke their language. Only 37% of women were given the opportunity to discuss the spiritual aspects of having breast cancer and only 33% had the chance to speak to someone with similar beliefs.

Contact with the SBN

Nearly all women (99%) were satisfied with the timing of the consultations with the SBN (Figure 3). In 81% of cases, the SBN helped to make treatment options clearer and 92% reported that the SBN had assisted them in the decision-making process. However, 11% of women would have preferred some changes to the timing of the consultations during the period of adjuvant therapy and 13.5% would have preferred more follow-up sessions. Seventeen percent reported that they would have preferred to see the SBN on request only.

Figure 3: Women's satisfaction with their consultations with the SBN

	Strongly Agree		Agree		Disagree		Strongly disagree	
	n	(%)	n	(%)	n	(%)	n	(%)
Diagnosis:								
Appropriate time to see SBN	129	(82)	26	(17)	1	(1)	0	
SBN made treatment options clearer	90	(54)	46	(27)	16	(10)	16	(10)
SBN assisted to make decision about treatment	96	(61)	48	(31)	9	(6)	4	(3)
Prior to surgery:								
Appropriate time to see SBN	137	(79)	35	(20)	1	(1)	0	
Speaking to SBN helpful at this stage	157	(80)	39	(20)	1	(1)	0	
After surgery:								
Appropriate time to see SBN	136	(76)	41	(23)	1	(1)	0	
Speaking to SBN helpful at this stage	157	(77)	45	(22)	1	(1)	0	

Overall appraisal of SBN intervention

Eighty-seven percent of women believed that the SBN had significantly contributed towards their care. Just over half (51%) of women indicated they would recommend to a friend that a hospital with a SBN was preferable, and a further 48% would advise only choosing a hospital with a SBN. Responses in the open question on how the SBN can best meet the needs of women with breast cancer mostly reiterated the quantitative findings of the present study, and there was consensus amongst rural women that the SBN was a valuable asset to women in remote areas.

Discussion

Our study found that women's perceptions of the SBN intervention were extremely positive. The SBNs were perceived by women to be well suited to the role of coordinator of their care, effective in communicating their needs to the treatment team, and were the one constant throughout the treatment process. Research has demonstrated that SBNs are effective in reducing psychological distress in women with breast cancer (Watson et al, 1988) and in increasing the early detection and referral of women with psychological morbidity for professional counselling (Maguire, 1980; Wilkinson et al, 1988). While the present study found that the SBN was effective in providing information on counselling services and emotional support to women and their families, a small proportion of women reported dissatisfaction with the amount of support provided by the SBN during adjuvant therapy. This is likely to have been due to the intervention terminating prior to the completion of adjuvant therapy. Although the SBNs were still available on "patient request", it appears that some women were not able to access her support as readily.

The SBNs were regarded as having provided the right amount of information at the time of diagnosis when treatment choices and prognostic issues were discussed and preparations for surgery made. These findings support the evidence that many women want detailed information about treatment options (NBCC, 2000b). It is likely that for women who were already clear about their treatment options, no further discussion about this issue with the SBN was necessary. However, our study supports the view that women also require access to information in the latter phases of adjuvant therapy.

Surprisingly few women in the present study were offered the opportunity to discuss the spiritual aspects of their disease. It is unclear whether the SBNs felt uncomfortable or inexperienced in dealing with this topic or whether the women themselves did not require support in this area. Nurses can feel ill-equipped to deal with their patients' spirituality (Piles, 1990), possibly due to the absence of guidelines for providing spiritual care (Ross, 1994). As there is evidence that spirituality can influence health (Ross, 1994) and may enhance patient's coping

skills (Goddard, 1997), it is important that the SBN acknowledges the spiritual beliefs of a patient and the impact they may have on their expectation of nursing care.

There were two limitations that need to be considered. Firstly, due to English proficiency being an eligibility criteria, there is likely to have been an under-representation of women from culturally and linguistically diverse backgrounds (CALD) who may require additional information on how to access appropriate resources for their language and culture. Secondly satisfaction surveys, such as the one used in the present study, can elicit highly favourable ratings (Ware, 1978). The levels of dissatisfaction reported in the survey may under-state women's concerns, and therefore their significance for further refinements to the SBN model. Despite these limitations, the findings of the present study suggest that the SBN model can improve the supportive care of women with breast cancer and complements existing health care services in Australia. Further research is needed to evaluate the efficacy of the SBN intervention over standard practice in Australian treatment settings using a RCT design and to explore the perceptions of Indigenous women and women from CALD backgrounds.

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