

Consumer perceptions of the effectiveness of a breast care nurse in providing coordinated care to women with breast cancer in Queensland, Australia

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KEY WORDS

Breast Cancer, Breast Care Nurse, Model of Care

ABSTRACT

Objective

To assess the effectiveness of a breast care nurse (BCN) in supporting women with breast cancer.

Design

Phone interview using a semi-structured questionnaire.

Setting

Large Australian regional health service.

Subjects

Women with breast cancer who either received care from the BCN (n=28) or did not receive care from the BCN (n=22).

Main outcome measure

Patient views of the value of information and support between the two groups.

Results

Significant differences were evident between the two groups. For 17 of 18 factors about information needs and quality participants supported by the BCN reported that more information and support needs were met than those without BCN support with statistically greater satisfaction ($p < .05$) demonstrated for five of the factors. There were also significant differences between the two groups for the timing of support pre and post treatment with those with BCN input indicating higher support in all cases.

Conclusion

The BCN model has been slow to be adopted in Queensland and this study supports continuation of the program and the creation of additional positions. There is clear evidence that a BCN role is accepted and effective in the health service. Furthermore the model of care coordination, support, information and referral has implications for other cancer streams.

INTRODUCTION

Breast cancer in Australia is diagnosed more than double the number of times of the next most common (bowel) cancer (AHIW and NBOCC 2009). Increased survival rates and lack of certainty of a cure present the challenge that women must find ways to live with their disease, confronting the short and long-term psychosocial as well as physical consequences. This in turn has led to a greater focus on providing holistic care to women with breast cancer and the need to address the reported unmet support need of participants (Connell et al 2006)

A degree of emotional distress is almost inevitable following diagnosis; however the level and type of that distress is likely to vary significantly between women and across time (NBCC 2000a). Psychosocial functioning is central to a woman's capacity to manage her breast cancer and psychological distress which is unrecognised, persistent and not treated is likely to have adverse effects including complying with treatment, and long-term survival (Love 2004).

The Australian National Breast Cancer Centre (NBCC) developed psychosocial guidelines for health professionals working with women with breast cancer (NBCC 2000b). In addition a number of strategies have been employed to improve the psychological wellbeing of women with breast cancer.

One strategy involves Breast Care Nurses (BCN) who provide continuity of support to breast cancer patients from diagnosis to completion of treatment. The position which has been in existence in the UK since the 1970's has been shown to enhance the early recognition of support needs, decrease psychological distress, and improve continuity of care and understanding of the disease and its treatment (Clacey et al 1988; Maguire et al 1983; Maguire et al 1980; McArdle et al 1996; Watson et al 1988).

The first BCN position in Australia was in an Adelaide hospital in 1979 (White 1999) but uptake was poor. Nearly 20 years later a national survey revealed that only 14% of women with early breast cancer had received structured support of three or more meetings with a BCN (Campbell et al 2006; Williams et al 2004). The benefits to those women agree with reports from Victoria (Cuss and Woodcock 2003; Oerlemans and Ham 2002), New South Wales (Szwajcer et al 2004) and South Australia (Halkett et al 2006). However despite positive results Australia's uptake of the BCN model has been small and largely limited to metropolitan areas. In the State of Queensland in 2008 at the time of this study there were only 16 BCN positions for a population of four million¹.

In 2008 the authors were commissioned by the State Health Department to provide an independent evaluation of the effectiveness of a BCN service one year after its creation. The perceptions of the clients are reported herein.

METHODS

This research reports on the perspectives of care received by women with breast cancer who had access to the BCN in 2007-2008 compared to women who had been treated for their cancer in 2005-2007 prior to the establishment of the BCN service.

Initial contact by health service staff determined consent to be interviewed by the researchers who were then provided with the patient's name and contact details. Phone interviews were conducted with 28 women who received BCN support throughout all or most phases of their diagnosis, treatment and recovery and 22 women who had no access to the BCN during any of these phases.

¹ In Queensland Specialist Breast Care Nurse is used in the public sector to denote nurses whose role is consistent with that outlined in the National Breast Cancer Centre competency standards (NBCC 2005).

Questionnaire

A questionnaire, developed for a previous evaluation (Eley et al 2008) was used. The questionnaire consisted of 20 questions each of which required selection of an answer from a Likert scale. At the end of the interview participants could add additional comments. The questionnaire covered coordination of care offered and the value and timing of information and support during diagnosis, treatment and recovery given by the BCN or in the absence of BCN by the provided service.

Comparisons were undertaken between Group A (women who had access to the BCN) and Group B (women who had no access to the BCN). Comparisons of answers were undertaken by chi square test with alpha set at 10% (i.e. $p < .1$).

Ethics approval was received from both the university and health service.

RESULTS

The mean age of participants at the time of their surgery was 55.0 years (SD = 9.9) for Group A and 52.5 years (SD = 11.0) for Group B. All participants had received surgery and one or more of the following treatments: chemotherapy, radiotherapy, hormone therapy.

Prior to the establishment of the BCN position patients received information from various health staff. After creation of the BCN position most information was provided by the BCN. Patients were asked to rate their information needs and the nature of quality of the information that was provided in a number of areas (Table 1). For all factors bar information about side effects Group A were more satisfied than Group B with statistically greater satisfaction demonstrated for five of the factors.

Table 1: Comparison between Group A and Group B responses in response to questions about Information needs and quality

Information needs	Your cancer	$p = .120$
	Your treatment choices	$p = .284$
	The treatment itself	$p = .142$
	Side effects of the treatment	$p = .943$
	Caring for yourself at home	$p = .018$
	Dealing with family issues	$p = .006$
	Support services	$p = .377$
	Travel or accommodation	$p = .178$
	Getting a prosthesis	$p = .176$
	Understanding how long you would be in hospital	$p = .151$
	Understanding what would happen after discharge	$p = .121$
	Information quality	Allowed you to show your real feelings
Was good at explaining things		$p = .167$
Gave you too much information		$p = .518$
Helped you cope or feel a little better about things		$p = .049$
Offered information at the time you most need it		$p = .126$
Where to seek spiritual support		$p = .111$
Was open to discuss alternative therapies with you		$p = .001$

The majority of participants (24 of 28) believed that the right amount and type of information was received from the BCN on all factors. Typical Group A responses were:

She was excellent... very knowledgeable.

She left me in no doubt as to what kind of cancer it was and the best way for it to be treated.

She sent me books that I could read.

In contrast only 10 of 22 Group B believed that the information they received from all sources was enough. Several participants indicated information not being presented in a suitable manner:

I would have liked to talk to someone.

I think they did their best nothing that was adequate

Two particular telling remarks were:

What I needed was emotional support specifically related to breast care.

We need women who are technically and psychologically trained... You need professional training with this sort of thing because it's a multifaceted problem ...the physical – the woman's self image about herself, the psychological and the fear of dying and the physical unwellness...."

Participants from both groups were asked to assess support to help them to emotionally deal with their breast cancer, make appropriate treatment choices, communicate effectively with their treatment team, manage treatment side-effects and deal with family challenges. Although in all cases more Group A were satisfied there were no significant differences between the two groups (Table 2).

Table 2: Comparison between Group A and Group B responses to questions about the type and timing of support and referral pathway options

Area supported	To deal with your diagnosis	p = .246
	To make choice about treatment	p = .244
	With relationship or communication with your doctor	p = .179
	To deal with concerns your family had about your cancer	p = .430
	To express and manage your feelings about the cancer	p = .221
	To deal with side effects	p = .185
Timing of the support	Before treatment	p = .038
	During treatment	p = .202
	After treatment	p = .035
Referral pathways	Social worker or welfare worker	p = .036
	Psychologist	p = .004
	Breast Cancer Support Service Volunteer	p = .019
	The Queensland Breast Cancer Fund Service	p = .007
	Breast Cancer Support Group	p = .030
	Physiotherapist	p = .020
	Chemotherapy nurse	p = .729
	GP	p = .613
	Community nurse	p = .015

There were also significant differences between the two groups for the timing of support pre and post treatment with Group A indicating higher support in all cases (Table 2). Significant differences were also found between the two groups for most of the referral pathway opportunities that were offered.

Participants reported they felt comfortable approaching the BCN for information or support because they knew that this was the focus of her work, and that she had time to respond to their needs. They were able to develop a trusting relationship in which they felt supported, were well informed, had someone to talk to, and someone to go to for help at any stage of their treatment. Accessibility of the BCN was mentioned as a highly positive feature of the role and having a familiar person always available to them was important and reduced their levels of anxiety.

DISCUSSION

The results of this evaluation clearly demonstrate that the BCN is highly instrumental in ensuring that there is continuity of care, and hence a better quality of care for women with breast cancer. Results add to other Australian data (Bourke 2004; Halkett et al 2006; Williams et al 2004) (Liebert and Furber 2004) and expand on our earlier findings in a nearby large regional setting (Eley et al 2008).

The incumbent breast care nurse in both locations was identified by participants as a highly motivated, knowledgeable, compassionate and dedicated person with “wonderful personality”. The research team reminded participants that it was the role and not the person which was under evaluation, but this was challenging as respondents had no prior BCN knowledge upon which to compare. However, despite this caveat it is our conclusion that the BCN role in these two services has directly improved quality of care for patients with breast cancer, via direct services to women with breast cancer, as well as through coordination of breast cancer services within the respective health services.

The comparison of results between those women with breast cancer who had access to the BCN, and those who did not, provided often poignant evidence of the need for the service. Participants with access reported that their care, support and referral was enhanced because of the support they received and would strongly recommend a hospital with a BCN to their friends. In contrast comments from participants without access to the BCN emphasise the psychosocial challenge confronting women who must come to terms with the diagnosis of a life-threatening illness as well as the consequences of her treatment. There is a clear recommendation from consumers for continuation of the program and additional study is now recommended to determine the actual savings to the health system as a result of the BCN program.

CONCLUSION

In conclusion this BCN model highlights the feasibility, appropriateness and effectiveness of having a highly experienced and knowledgeable advanced practice nurse provide a personalised service to patients and their families whilst working with other health professionals within the health service to ensure coordination of care for their particular patient group. Furthermore while health systems grapple with increases in demand for chronic illness care, the success of this role leads almost inevitably to a question about the applicability of it to other cancer streams and indeed to other disease states.

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