

## **The value of a Breast Care Nurse in supporting rural and remote cancer patients in Queensland**

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**Abstract**

The role of the Breast Care Nurse in Queensland's Supporting Rural Women with Breast Cancer Project was evaluated by mixed methodology. Through questionnaire and interview patients provided views about the nurse's role under categories of *Awareness, Access, Coordination, Information and Psychosocial, Emotional and Practical support*.

Of the 51 participants 37 resided in rural and remote areas with 18 living between 100 and 500 miles from specialised breast care services. The BCN met with patients at their regular hospital visits and was available by telephone at any time. There was overwhelming agreement among the participants that the timing of contact, ease of accessibility, information provided and support offered were extremely valuable in making their treatment and recovery easier. The vast majority of participants would recommend hospitals with a BCN to their friends.

Members of the multidisciplinary care team provided views on *Awareness of the BCN, Influence on Care Management, Communication and Patient Outcomes*. They recognised the benefits of the BCN to patients and to coordination and liaison of the team.

The findings concur with unpublished Australian reports that demonstrate the success of dedicated Breast Care Nurses. The BCN model of care could be used successfully to support other medical conditions.

## Background

Breast cancer continues to be the most commonly diagnosed cancer and cause of death of women in Australia.<sup>1</sup> Within the country the disease has a relatively high profile owing in part to celebrity victims such as the singer Kylie Minogue and Jane McGrath, wife of Australian cricketer Glen McGrath. Whilst greater access to screening services and improved diagnosis have contributed to a doubling of yearly diagnosed cases in the last quarter century, earlier detection and improved treatment have reduced mortality.<sup>2</sup>

The incidence of breast cancer is slightly lower in regional and remote areas as compared to metropolitan areas.<sup>3</sup> Nevertheless, with 36.3% of the Australian population living outside major cities,<sup>4</sup> health service demands related to the disease are high. Long travel distances for specialized treatment, the financial burdens of travel and accommodation, disruption to family lives, lack of treatment choice, difficulty in access to information and unmet psychological needs have all been identified as special needs for cancer patients from rural and remote areas.<sup>5-7</sup> These factors may contribute to the fact that women from rural areas are more likely to have a mastectomy.<sup>6</sup> Despite having more needs than their city counterparts rural women receive less financial support and yet are less likely to ask for assistance.<sup>8</sup>

Psychosocial support plays an important role in the provision of holistic care to women with breast cancer as well as to their loved ones. In recognition of this need psychosocial clinical practice guidelines were developed by the Australian National Health and Medical Research Council (NHMRC).<sup>9</sup> These guidelines then formed the basis for a broader set of guidelines to apply to adults with any form of cancer.<sup>10</sup>

In 1995 the Australian Federal Government stated that they had a goal to address the specific needs of breast cancer patients.<sup>11</sup> This proclamation resulted in a number of national and local strategies to improve the psychological wellbeing of women with breast cancer. For example the Breast Cancer Support Service provided by the Cancer Council supports women with breast cancer on a one-to-one basis with women who themselves have had breast cancer. Survey results show that women who meet someone else with similar experiences consider this to be beneficial.<sup>12</sup>

Another ongoing strategy is that of the Specialist Breast Care Nurses (also referred to as Specialist Breast Nurses or Breast Care Nurses and identified hereafter in this paper as BCN) who provide continuity of support to breast cancer patients from diagnosis to completion of treatment. Prior to introduction in Australia the position was long recognised in the United Kingdom where studies have shown BCNs enhance the early recognition of support needs, decrease psychological distress, and improve continuity of care and understanding of the disease and its treatment.<sup>13-17</sup>

Although the first positions of BCN were established in Australia in 1979 it was not until the 1990's that the number of positions really expanded.<sup>18</sup> The role of the BCN in Australia is described to comprise of 11 role elements ranging from specialist nurse through educator and advocate to manager.<sup>19</sup>

A national survey of 544 women with early breast cancer was undertaken in 1997 by the National Breast Cancer Council. That single study has provided the results for the majority of the peer review journal articles that describe the support of breast cancer patients in Australia.<sup>12,</sup>

<sup>20-27</sup> The survey's authors concluded that there was considerable evidence to show the benefit of the BCN. However they noted that the small numbers of BCNs nationally meant that relatively

few women saw a BCN on more than one occasion and fewer than one in six received structured support. Comparison between women who did not see a BCN and women who had three or more contacts revealed that the latter group received more information about side effects, clinical trials, self support and family support. Not surprisingly it was concluded in the report that there was a need to improve access to the specialist breast nurses.

The Specialist Breast Nurse Project ran in four centres in the mid 1990's. It demonstrated that BCNs could be effectively employed in various locations across Australia.<sup>28-31</sup> Studies in Bendigo, Victoria,<sup>32</sup> Hume, Victoria<sup>8</sup> and Sydney, New South Wales<sup>33</sup> evaluated consumers, the BCN and other health professionals. Results from all the studies demonstrated the overall value of the BCNs who were perceived by patients to provide an invaluable contribution in providing information and emotional support. Health professionals reported that the nurses improved functionality of the multi-disciplinary health teams and provided valuable information to patients at all stages of their treatment. **These three studies were all undertaken a decade ago and only the Sydney study has been published.**

Despite the overwhelming positive response demonstrated in these evaluations, widespread introduction of BCNs to states such as Queensland has been slow. There is still little uniformity across or even within states in names or qualifications. Furthermore although the placement of BCNs based in rural settings have been demonstrated to have benefit to rural and remote patients,<sup>28</sup> access to the nurses remains difficult for many women.<sup>8</sup>

**Prior to 2001 there were only four BCN positions in the public sector in Queensland. By 2007 this had increased to 16 positions.** One such position is in Toowoomba where a project entitled Supporting Rural Women with Breast Cancer started in 2005. **The project had the goal to ensure that a new model of care was implemented by the local health service and that model**

was in accordance with NHMRC guidelines for support of women with breast cancer. A full time BCN position was integral to that model. The specific objectives of the project were to provide a) a multidisciplinary care team, b) a coordinated approach to management and treatment, c) adequate information and support to patients and their families and d) referral to appropriate psychological services.

In 2007 an independent evaluation of the role of the BCN was commissioned by the Cancer Screening Services Unit of Queensland Health. The results of the evaluation were to be used to inform future strategy. The results of that evaluation are presented in this paper.

## Materials and Methods

### Location

Toowoomba is located 70 miles west of the Queensland state capital Brisbane. The town has approximately 95,000 people. It is designated inner regional and highly accessible to services including health services<sup>34</sup>. The Toowoomba public health system also provides some specialist services to people living in a) the moderately accessible outer regional areas within the Toowoomba and Darling Downs Health Service District (population 240,000) and b) the remote and very remote areas of the South West Health Service District (population 25,000). The latter District extends almost 900 miles west from Toowoomba to the state and territory borders of South Australia and the Northern Territory, respectively.

### Design

A telephone questionnaire and participant commentary enabled the collection of both frequency and descriptive data.

### Questionnaire

A questionnaire was developed for the evaluation. The specific objectives of the Supporting Rural Women with Breast Cancer Project formed the basis for the categories used in the questionnaire. Consequently the questionnaire explored breast cancer patients' opinions of the BCN under categories of *Contact, Access, Coordination, Information, and Psychosocial, Emotional and Practical* support. Three other questionnaires that had been used for studies on breast cancer support programmes in other health service districts in Australia were consulted in the preparation of the specific questions. These questionnaires are unpublished but were made available to the research team.

The questionnaire consisted of 20 questions each of which required a yes/no response or selection of an answer from a Likert scale. It was administered over the telephone by an experienced female project officer and took 15 - 20 minutes to complete. After completion of the questionnaire participants were offered the opportunity to comment on any aspect of their association with the BCN. These comments provided the qualitative component of the research.

## Participants

### *Patients*

From the establishment of the full time BCN position in July 2005 until December 2006 120 women were offered support following their diagnosis of breast cancer. Their contact details were maintained on a database. Groups of 5-6 women were selected at random from the database and contacted by telephone. The purpose of the evaluation was explained to them and they were asked if they would participate. Once a time for administering the questionnaire was arranged with one group another group were selected and contacted. The rationale for this approach was to ensure that there was minimum time lag between contact and interview. Most interviews took place within one week of initial contact.



### *Other stakeholders*

The views on the position of the BCN were obtained from other stakeholders within the health service district. These were mostly clinical staff within the multidisciplinary team involved in the diagnosis, treatment and care of the breast cancer patients or senior managers within the health service districts. A self-administered mail questionnaire collected these stakeholders' views on their *Awareness of the BCN*, the BCN's *Influence on Care Management*, *Communication within the Multidisciplinary Team* and *Patient Outcomes*.

The study was approved by the Human Research Ethics Committees of both the university and the State Health Department. Receipt of a signed consent form was required for any data from patients to be used. Return of the questionnaire by mail was deemed to indicate consent by the clinical staff.

## **Results**

### *Participants*

Over a two-month period 69 of the 120 women were contacted, 63 agreed to participate and 51 actually participated. Twelve women did not participate because a suitable time could not be arranged. At the end of the two months data saturation was considered to have been achieved and no further contact was initiated. The participants ranged in age from 38 to 79 years with 80% being 50 years or older (Table 1).

### *Residence of the patients*

Fourteen women lived within 10 miles of the breast care services at the hospital. A further 19 came from rural locations within a 60 mile radius of town. The remaining 18 resided in small communities or on farm properties between 100 and 500 miles from Toowoomba.

### Surgery and treatment regimen

All 51 women had surgery which involved **either** lumpectomy **or** mastectomy or both **procedures**. Following surgery 23 (45%) had chemotherapy, 26 (51%) radiotherapy and 14 (27%) both chemotherapy and radiotherapy. **Chemotherapy was offered in Toowoomba, however for radiotherapy treatment patients had to travel to Brisbane.**

### Breast cancer patients first contact with the BCN

The majority of participants (28, 55%) had their first contact with the BCN either at diagnosis or within two days of diagnosis and a further 19 (37%) during the time leading to surgery. All but four women said that the **time of their first contact was at the right time**. Three considered that **their time of first contact was a little early and one a little late**.

### Access to the BCN

**Following their** surgery patients returned to the hospital at regular intervals for treatment or assessment. The BCN met with patients during these **visits, however** between visits women were able to contact the BCN by telephone or in person. The vast majority (87%) of participants indicated that contact with the BCN was easy (36%) or very easy (51%). **The timing of consultations was considered to be well timed by 48 women (95%) and all 51 women stated the time made available for consultation was about right**. Only two of the fifty-one women said that the level of contact was not *about right*. The two exceptions considered the contact to be *too little* (n = 1) or *far too little* (n = 1). In response to the question “Do you think that having the same BCN as your contact person during your treatment was of any benefit?”, 45 said that it was of *great benefit*, three a *little benefit*, one *no benefit* and one was *not sure*.

### Coordinating care

Table 2 presents the women's rating of the help offered by the BCN in the coordination of their care. Ratings were extremely positive, with all women for whom support was relevant stating that the *right amount* was offered.

#### Information needs

The type of information needs of the breast cancer patients were largely met by the BCN (Table 3). Similarly the quality of the information offered was positively received (Table 4). Information on where to find spiritual support and alternative therapies were not applicable to many participants.

#### Psychosocial support

With few exceptions there was agreement or strong agreement to all statements related to psychosocial support (Table 5). One woman however *strongly disagreed* with all the statements.

#### Emotional support

All but two women were *satisfied or very satisfied with* the emotional support that they received from the BCN pre, during and post treatment.

#### Practical Support

Practical guidance about travel and accommodation was considered to be *about right* by all 43 women for whom support was applicable. This guidance supported women from rural and remote areas who came to Toowoomba and all women who had to visit Brisbane for radiotherapy. Practical support was also offered on prostheses. A third of the women (17) said that this latter information was not required. The remainder considered the amount of help to be appropriate.

### Advice to friends

The vast majority of women (n = 46) said that if they had a friend with breast cancer they would recommend that they seek treatment from a hospital with a BCN. Thirty-nine of the 51 respondents (77%) were more emphatic and stated that they would advise friends only to go to a hospital with a BCN.

### Comments

After completion of the questionnaire additional comments were offered by 47 of the 51 women about the BCN and the service provided. Comments were enthusiastically offered and without exception were positive about the BCN and the role that she had played.

*I wouldn't have made it without the BCN. I put a lot of my wellness down to her help.*

Access and availability of the BCN was a common theme.

*She was more approachable than the doctor because of her role.*

*She is still available eighteen months on.*

Women who lived in rural and remote areas appreciated the contact.

*[BCN] is really important - means you are not isolated, you have a lifeline.*

*The BCN was waiting which made a big difference because my family couldn't be with me.*

*....especially for my husband - not much out there for him.*

Emotional support was very important.

*I would have died without her – literally. I completely crashed and went to pieces.*

*You do feel a bit alone and having support [of the BCN] gives you strength and courage.*

*Someone understands. Somebody gave a damn whether you lived or died within a system.*

Support was acknowledged not only to the patient but also to the rest of the family.

*My husband and I couldn't have gotten through this without her.*

*She rang on the speaker phone and spoke to the whole family.*

*I don't know how my family would have coped without her.*

Information and advice offered by the BCN was welcomingly received.

*So many questions small and big – I can always ring her.*

*Thank goodness someone explained it - Aboriginal people don't understand this stuff - they were very good with me.*

Continuity of support was identified as an important issue.

*She already knows you and understands your condition – its been 12 months but I rang her about something just last week.*

The value of the support offered by the BCN is perhaps best summarised by the statement

*The BCN was absolutely marvellous. I hope and pray that they never do away with them.*

*They are really and truly needed. The one on one is excellent.*

### Stakeholders.

Responses to the mailed questionnaire were received from 18 staff comprising of 13 Nursing Officers, three Medical Officers and two senior managers. Fourteen of the 18 respondents were members of the multidisciplinary team and were in contact with the BCN at least weekly.

Awareness of the role of the BCN was high with all but one respondent identifying the BCN as being both the provider of support and information to the patient and also as an important link to the team of health professionals.

All clinical staff noted that the BCN had improved communication between themselves and patients. All but one of the 18 respondents stated that the BCN participated in multidisciplinary team meetings and all respondents agreed that the BCN was able to influence decisions. Stakeholders believed that appropriate referrals had been made and were unanimous in the opinion that the BCN supported high quality care. Service coordination and continuity of care were both seen to have improved because of the project.

Positive comments offered by the stakeholder included:

*The Breast Care Nurse saves time and resources.*

*It is important to be able to guide the women through the complex multi-disciplinary areas that are involved in their care.*

*Generally women are in a fragile state of mind when they come for surgery so meeting the Breast Care Nurse gives them a familiar face to relate to pre and post surgery.*

*There is no question about the Breast Care Nurse not improving services to patients.*

## **Discussion**

Breast Care Nurses have existed in Australia for many years. However with the exception of the State of Victoria update has been relatively slow. This is despite the documented value of the BCN both overseas and in Australia. Admittedly peer reviewed journal papers about BCNs in Australia are limited and relate to studies undertaken a decade ago.<sup>20, 30, 33</sup> **Since that time there have been many changes within the health system with relation to management of breast cancer patients. The most notable of these** are the production of guidelines for the socio-psychological management and support of breast cancer patients<sup>9</sup> and the competency standards for BCNs.<sup>29</sup> To our knowledge this is the first study that reflects current information of breast cancer patients' views on the BCN.

A limitation to the study is that it did not offer an opportunity to interview women who had not received any support at all. Furthermore it is difficult to remove the influence of the personality of the incumbent from the general role of a BCN. The incumbent is a highly personable, highly motivated and dedicated professional who is loved and respected by patients and team members alike. Her personal attributes in no small way contribute to the success of the

programme. Whether the same study results would have been obtained had the BCN been without these same attributes can of course be questioned.

These two limitations do not detract from the overall value of the evaluation. Nor do they reduce the primary conclusion of the study that the vast majority of the women's experiences during their breast cancer treatments had been made positive because of the support they received from the BCN.

Only 51 of the 120 women who had received support participated in the survey. However those who did participate were selected completely randomly irrespective of their age, treatment received or home location. There is therefore no reason at all to suspect that the results are not representative of the entire cohort of 120 women.

For women in the Southern Area of Queensland access to many health services requires travelling long distances. This is particularly true for the largely remote and very remote South West Health Service Division. Although a mobile breast screen service visits some rural and remote locations, all diagnostic, treatment, surgical and follow-up services are only offered in Toowoomba, or in the case of radiotherapy, in Brisbane. The travel, financial and psychosocial burdens for breast cancer patients from rural and remote patients are well documented.<sup>5-7</sup> The development of services in regional towns such as Toowoomba has certainly helped with travel and accommodation costs, whilst the services of a BCN have clearly assisted in reducing the trauma of the diagnosis and treatment and the stress of family separation.

The BCN quite clearly provided what is recommended by the National Breast Cancer Centre Psychosocial Working Group<sup>9</sup>, namely that a specialist breast nurse's role is to provide continuity of care through counselling, information and support relating to all aspects of breast



care for women with breast cancer. In addition to that role we concur with others<sup>32</sup> that the attributes of reliability and availability are also important to the success.

Contact with the BCN met with the Australian model of care recommendations that the BCN either be present at the time of diagnosis or have contact with the woman within 48 hours.<sup>31</sup> Subsequent contact with the BCN was also easy thus demonstrating the value of the full-time position that was created. The incumbent was available for consultation at any time and several patients noted that contact was being maintained by them at the time that this study was undertaken which in some cases was close to two years after diagnosis.

Patients in the UK expressed the desire for continuity in BCN support. The preferred service was one in which the BCN had time, skills and knowledge.<sup>35</sup> Our participants also noted that continuity of support from the BCN was important and considered that having the same BCN was a major factor to the success of the programme.

Our results concur with Oerlemans<sup>32</sup> that women are comfortable talking to a BCN. The BCN is considered to be more approachable than doctors and has more time to attend to the patient's needs. These results are supported by the observations made by patients in the UK who stated that owing to the hurried nature of consultations and lack of continuity in medical staff they felt uncomfortable expressing emotional concerns and asking questions.<sup>35</sup>

A Canadian based study of breast cancer patients and their husbands found unmet need especially in relation to information offered to male carers from rural areas.<sup>36</sup> A large portion of our questionnaire addressed this issue. The perception of the amount of information that was provided and the timing of that information was ascertained. Our patients noted that information

had been appropriate, well explained and given at the right time. Several women also noted that BCN had helped them understand information given to them by other health professionals.

Rural patients said that the communication between them and the BCN was a vast improvement over the normal isolation experienced by rural families. National improvements to phone and broadband coverage will continue to support opportunities for increased communication for health related matter.

Psychological morbidity in breast cancer patients is reported to be common, greater in younger women and to have needs that are often unmet.<sup>37-39</sup> Unmet needs may be greater for rural cancer patients<sup>6-7</sup> where there is a shortage of psychological support services.<sup>40</sup> It is of great significance therefore that not one of our 51 participants reported that they sought psychological support other than that provided by the BCN.

Notable in studies of BCNs is the omission of financial benefits to the health service by their activities. These include savings in the direct cost of breast cancer patients' health care. We suggest that BCN interventions reduce additional management post surgery, for example as a result of infections. In a UK study those women who received BCN support twice in the first year post diagnosis also reported fewer physical problems<sup>41</sup>. Not only is the information and support offered by the BCN likely to reduce the direct health costs for the breast cancer patients, but health professionals will be able to realise time savings which may be used to benefit of other patients. Only when these costs are quantified will the true benefit of any BCN programme be realised. **Future research is recommended to determine these figures.**

In summary the results collected in the study demonstrate that the BCN position was considered to be of great value to patients from regional, rural and remote environments. The BCN offered

valuable information, support and advice and was instrumental in ensuring that there was continuity of care. There was a clear recommendation from consumers and stakeholders alike for continuation of the programme. The model of care offered by the BCN project is one that could be mirrored for other illnesses although additional study is recommended to determine the actual savings to the health system.

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Table 1. Ages of women (n = 51) who participated in the study

Table 2. How women (n = 51) rated the amount of help offered by the BCN in care coordination

Table 3. How women (n = 51) rated the type of information provided by the BCN

Table 4. How women (n = 51) rated the quality of the information provided by the BCN

Table 5. How women (n = 51) rated the psychological support provided by the BCN

Table 1. Ages of women (n = 51) who participated in the study

(a) Age range (years)	(b) Number
(c) <40	(d) 1
(e) 40 – 49	(f) 10
(g) 50 – 59	(h) 19
(i) 60 - 69	(j) 12
(k) 70 - 79	(l) 9
(m) Total	(n) 51

Table 2. How women (n = 51) rated the amount of help offered by the BCN in care coordination

The help provided by the BCN in ....	Wanted more	Right amount	Wanted less	Not applicable
..understanding the roles of the different people involved in my treatment	0	45	0	6
..understanding the information I received from different doctors and health workers	0	46	0	5
..communicating my needs to other health workers	0	40	0	11
..making appointments for me	0	44	0	7
..making transition to the next treatment stage easy	0	45	0	6

Table 3. How women (n = 51) rated the type of information provided by the BCN

Information offered about	Wanted more	Right amount	Wanted less	Not applicable
Breast cancer	0	45	1	4
Treatment choices	0	44	1	5
The treatment itself	1	44	1	4
Side effects of the treatment	0	43	2	5
Caring for myself at home	0	44	1	4
Support services	1	41	1	7

Table 4. How women (n = 51) rated the quality of the information provided by the BCN

<b>The BCN ....</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>Not applicable</b>
..provided information that allowed me to share my feelings	42	4	0	0	5
.. was good at explaining things	41	7	0	0	3
.. gave me too much information	0	2	40	6	3
.. said things that helped me cope or feel a little better about things	39	4	0	0	7
.. offered information and support at the times when most needed	41	7	0	0	3
.. offered sufficient information of where to seek spiritual support	21	4	2	0	23
.. was open to discuss alternative therapies with me	25	5	1	0	20

Table 5. How women (n = 51) rated the psychological support provided by the BCN

<b>Support by the BCN helped me ...</b>	<b>Strongly agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly disagree</b>	<b>Not applicable</b>
..to deal with my diagnosis	38	5	2	1	5
..to make treatment choices	32	4	4	1	10
..with communication with your doctor	27	6	1	1	16
..to deal with concerns my family had	35	4	0	1	11
..to express and manage my feelings	34	7	2	2	4
..to deal with side effects	33	6	0	1	11