NATIONAL BREAST
CANCER CENTRE
Incorporating the
Ovarian Cancer Program

Specialist breast nurses: **an evidence-based model for** Australian practice

Specialist Breast Nurse Project Team

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Foreword

The diagnosis of breast cancer is usually a traumatic event in a woman's life. She is immediately thrust into a totally foreign world-with a new language, new concepts, new surroundings and new faces. Nothing feels like it was before, and for many women the overwhelming feeling is one of aloneness.

Each woman is required to make several decisions for which she is often ill-equipped. These come at a time when she is most anxious for herself and her family and when she is still reeling from the shock of her situation. She needs to feel she has the information she requires to be fully informed about her own situation, her options and the resources and services available to her. She needs to have a medical team in place to ensure that she receives treatment and care tailored to her needs. She needs to believe that the team is concentrating on her, and not just on the cancer diagnosed within her.

In October 1998, hundreds of women came to Canberra from all States and Territories to attend the First National Breast Cancer Conference for Women. We worked to identify the most crucial strategies which would make a difference for Australian women diagnosed with breast cancer in the future. It is significant to note that the provision of specialist breast nurses was seen as the top priority. The participants recognised the specialist breast nurse as being in a unique position within the multi-disciplinary team setting to offer information, emotional and practical support when these are most needed.

Those of us who had access to a specialist breast nurse spoke passionately about the help given. A common comment was "I don't know how I would have coped without her!". For women undergoing several months of treatment which might include surgery, radiotherapy and chemotherapy, it is so important to have one constant link – a familiar face in an unfamiliar world – to offer continuity of care. The specialist breast nurse is also able to identify those women who may require referral to other services, including psychological and psychiatric support.

The challenge now is to improve access for Australian women with breast cancer to a specialist breast nurse and to make sure that the role is based on evidence. It is also clear that in Australia the specialist breast nurse will need to perform different tasks in different locations. A specialist breast nurse working in a capital city will not work in the same way as a specialist breast nurse working with women in the outback. Her role will vary according to local circumstances and to the range of needs of the women with whom she is working.

This NHMRC National Breast Cancer Centre report investigates the various tasks the specialist breast nurse may perform and the services she may provide to the woman and to her medical colleagues. It also considers the costs, issues and challenges involved in the role.

Most importantly, it provides clear evidence to support the view held by women who have experienced breast cancer: that the specialist breast care nurse is uniquely positioned to give real assistance in a myriad of ways to a woman at various stages of her breast cancer journey.

Lyn Swinburne
National Coordinator
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Executive summary

Background

For Australian women the lifetime risk of breast cancer is one in 12. Despite advances in treatment there have been significant shortcomings in the level of supportive care available, with women with breast cancer experiencing unmet informational, practical and emotional needs. Specialist breast nurses (SBNs) were introduced in the United Kingdom to provide support for women with breast cancer, and the beneficial impact of their care has been demonstrated in randomised control trials. The SBN role is less developed in Australia. The aim of this study was to explore the implementation, acceptability, impact and costs of a SBN model of care in diverse Australian settings.

The evidence-based SBN model of care

The SBN model of care developed in this project was based on the evidence-based recommendations of current oncology, and psychosocial clinical practice guidelines for the care of women with breast cancer (summarised in NHMRC NBCC, 2000). In particular, the role required the SBN to assess and respond to women's needs for information, practical assistance, emotional and psychological support, and to encourage an awareness of their cultural and spiritual beliefs. The model emphasised the role of the SBN in providing continuity of care for women with breast cancer.

The model was operationalised in the "5 in 12" clinical pathway, which:

- included five prescheduled consultations at key treatment phases- namely, diagnosis, pre-operative, post-operative, and two follow-up appointments across a 12-week period post diagnosis;
- allowed flexibility for women to make additional appointments with the SBN as needed; and
- provided a clear structure (in the form of a checklist of core areas) in which SBNs assessed a woman's needs at each scheduled consultation.

The SBN Project

The project was conducted at four collaborating treatment centres, selected through a national competitive tendering process. These were selected as centres of excellence and diversity in health service delivery. The centres were Royal Adelaide Hospital, Royal Perth Hospital, Dubbo Base Hospital (a rural treatment centre in NSW) and the Inner and Eastern Heath Care Network in Melbourne (incorporating Alfred Hospital, Peter MacCallum Cancer Institute, Maroondah Hospital, and a private surgical setting).

Seven senior grade nurses were trained to deliver the evidence-based SBN model of care. The training was based upon the *NHMRC's Clinical practice guidelines for the treatment of early breast cancer* and the National Breast Cancer Centre's *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*. The SBNs also attended the National Breast Cancer Centre's communication skills training program. The SBNs received regular supervision to ensure adherence to the clinical pathway. They also completed detailed research logs recording their intervention with each woman and their daily professional activities.

A total of 240 women with a new diagnosis of early breast cancer were recruited into the treatment arm of the study. They completed evaluations of their care by self-report questionnaire at two and six months after diagnosis and a comprehensive telephone interview up to 12 months after diagnosis. The telephone interview was also completed by 133 women treated at the Collaborating Centres prior to the study (the retrospective control) and a representative national sample of 544 women with early breast cancer who participated in a separate study (The National Consumer Survey).

Additional data were collected through observational studies, telephone interviews and face-to-face meetings with the SBNs and members of the treatment team to evaluate the economic feasibility of the model, factors affecting caseload and the acceptability of the SBN role within each treatment team.

Results

The clinical pathway

- The clinical pathway was successfully implemented across diverse settings. It specified core areas for intervention but retained enough flexibility to be adapted in the local conditions.
- The women in the study reported that they used the SBN for support and overwhelmingly endorsed the role. Eighty-eight percent of women believed that the SBN made a significant contribution to their care. Overall, 99% of women reported that they would recommend seeking treatment for breast cancer at a centre that provides a SBN.
- Approximately a third of the women in the study required more than 12 weeks to complete the five scheduled consultations. It may be necessary to allow for longer intervention as needs arise.

Benefits to women

Information

Compared with women in the retrospective control and the National Consumer Survey, women seeing a SBN in the study:

- received more information about aspects of breast cancer and treatment-for example, audio-tapes of consultations and hospital fact sheets;
- were more likely to be told about clinical trials and overall to participate in these trials; and
- were more likely to report having had, or considered having, reconstructive surgery (if this was appropriate).

Emotional support

- The study confirmed the high levels of psychosocial needs among women with breast cancer. At diagnosis 30% of women were found to have multiple risk factors for psychological morbidity. According to a psychological screening questionnaire (GHQ-12) completed at two months after diagnosis, 35% of women experienced anxiety or depression and 25% experienced the same at six months.

- Following the "5 in 12" clinical pathway, the SBNs were able to identify women's psychological needs and to adjust their intervention accordingly. In the scheduled consultations, SBNs were found to have identified up to 72% of women experiencing high levels of distress. In consultations initiated by women, however, SBNs were less successful in identifying women's distress.
- SBNs referred few women with likely anxiety and depression to specialist services, due to encountering difficulties in accessing mental health services and in encouraging women to take up the offer of referral.
- The SBNs' emotional support role was rated positively by the majority of women. However, a notable minority reported difficulties sharing their feelings with the SBN and between 10% and 15% indicated they would have liked more emotional support.

SBN skills, training and caseload

To implement the evidence-based model of care SBNs required diverse and advanced knowledge, skills and experience, including:

- comprehensive knowledge of breast cancer and its treatments;
- ability to liaise with, and educate, treatment team members;
- skills in the provision, tailoring and clarification of information;
- good emotional support and counselling skills;
- psychological assessment skills;
- effective time management skills; and
- advanced clinical skills.

In their day logs SBNs recorded that they spent 54% of their time on clinical activities. The "5 in 12" clinical pathway meant that they accumulated a significant caseload. During the study the average number of women seen by the SBNs increased from 25 to 35 per week with the SBNs reporting significant time pressures to achieve the latter level and the accompanying project documentation.

The diverse skills of SBNs were valued within the treatment centres, and SBNs needed to allocate time for teaching and attending meetings. A significant part of their time was also taken up by administrative activities.

Multidisciplinary team

The SBNs in this study were well received by, and integrated into, multidisciplinary teams, with only low levels of role conflict occurring. An understanding of the SBN role within the team and good communication between team members was essential for the integration of SBNs and the smooth functioning of the team. The SBN also played a key role in facilitating women's understanding of the multidisciplinary team.

Economic evaluation

- The financial costs of employing SBNs in this study ranged from $2635 per month for a half-time position through to $5500 for a full-time position.
- An observational study of one public breast clinic indicated that the presence of a SBN may have an impact on the duration and nature of clinical consultations with women with breast cancer. The medical and nursing staff tended to spend more time with women who have symptoms indicative of breast cancer when a SBN was present. The SBN's presence also led to more discussion about treatment and inpatient management.
- The project highlighted potential approaches to a full economic assessment.

Recommendations

In this demonstration project, the evidence-based specialist breast nurse (SBN) model of care has been found to be a promising development in the provision of supportive care for women with breast cancer across diverse Australian treatment settings. The following recommendations, based on the findings of the project, are made to assist treatment centres considering implementing one or more SBN positions.

SBN skills and qualifications (Chapters 5, 9 and 10)

To function optimally in the role the SBN requires:

- postgraduate qualifications in oncology or breast cancer nursing;
- training in communication and supportive care skills; and
- a commitment to, and opportunity for, continuing education.

On the basis of the skills required and responsibilities undertaken, it is also recommended that the evidence-based SBN position is given a senior grading. The likely cost of employing a full-time SBN will be $5500 per month.

The relationship between the SBN and other treatment team members (Chapters 3 and 5)

- The SBN should be recognised as an integral part of the multidisciplinary team.
- The SBN role should be negotiated within each team from the outset, taking into account the characteristics of the treatment centre and its other team members.
- Role overlap may occur between the SBN and other team members, but effective communication within the team can promote this overlap as strengthening the overall functioning of the team.

Psychological support and supervision (Chapter 8)

- SBNs need effective skills in identifying and managing women with high levels of psychological distress.
- The evidence-based SBN model of care requires communication skills training, to enable the SBNs to elicit and respond to women's feelings and psychological symptoms.
- Ongoing access to psychological supervision is recommended for effective implementation of the clinical pathway, SBNs' skill development, and management of psychological impact on SBNs themselves.
- Reliable access to a mental health service is necessary to provide comprehensive care for women.
- More information is needed about the uptake of psychological referrals by women with breast cancer and about factors inhibiting women's likelihood of accepting a referral.

Adapting the clinical pathway to local conditions (Chapters 2, 3 and 4)

- The clinical pathway needs to be flexible in terms of the number and timing of sessions and the total duration of the intervention. This enables SBNs to take into account the needs and wishes of individual women, based upon their level of psychosocial risk, existing support networks and adjuvant treatment requirements.
- In some cases, women may need to be treated at more than one treatment centre. Adherence to the clinical pathway for each treatment phase enables clear documentation of women's needs and continuity of support across treatment centres.

Caseload for a full-time SBN (Chapter 10)

- The sustainable caseload for each SBN will vary according to her experience and local conditions. However, when implementing the clinical pathway, it is important to consider that the number of women receiving active supportive care across the treatment phases will accumulate. It is essential to review caseloads to ensure that each woman has adequate access to the SBN and that the SBN is not overburdened.

- On the basis of the "5 in 12" clinical pathway, it is recommended that the SBN's caseload range between a total of 36 and 48 women with breast cancer. This allows for three-four newly diagnosed women to be added to the caseload each week. This caseload also enables the SBNs to maintain a full range of relevant professional activities, in keeping with their senior grading.
- It is important to note that if the intervention period is routinely extended (either by number of weeks or number of scheduled sessions) then the SBN's caseload will increase proportionately. For example, seeing women for 16 weeks (rather than 12) would result in a SBN caseload of 48-64 in total.

Resource implications of the SBN position (Chapter 9)

There is a need for further economic analyses to determine the longitudinal resource implications of the SBN and the role's benefit to the women, other treatment team members, and the community.

Chapter 1: Introduction

Breast cancer is the most commonly diagnosed cancer in Australian women, with approximately 10,000 women diagnosed each year, and remains the leading cause of death from cancer in women (Australian Institute of Health and Welfare, 1998). An Australian woman's lifetime risk of developing breast cancer is one in twelve.

Submissions to the House of Representatives Standing Committee on Community Affairs (1995) suggest that some women experience the management and treatment of their breast cancer as fragmented and uncoordinated. Many women felt treatment was directed at their body parts, rather than towards them as people. Others reported problems accessing adequate information, and rarely receiving their required level or frequency of communication with members of their treatment team. Women reported that diagnoses were often conveyed in an abrupt manner, and that their questions were met with resentment. Despite the high incidence of psychological morbidity in breast cancer patients (Kissane *et al.* 1998), practical and psychosocial counselling and support were seldom offered. The lack of a coordinated support system made access to appropriate services for women and their families difficult.

In a recent Australian survey of women diagnosed with early breast cancer (Williams *et al.* in review 2000*)* some women reported failing to receive enough information or support while undergoing treatment. Sixteen percent of women felt they required more support during diagnosis and treatment and 22% of women believed their family required more support from the treatment team. Fifteen percent of women reported that they would have preferred more information about their treatment. Specific information needs were also unmet: only 29% of women in relationships were offered resources for their partners; and 11% of women with children were offered resources for their children.

These findings are comparable with international studies assessing the needs of breast cancer patients. A review by Girgis and Foot (1995) found that six of eight studies reflected high levels of patient dissatisfaction with the amount of information received. In another study, women reported a need for additional information about their cancer and its treatment (Foot, 1996). The type of information sought may change during the course of treatment (Luker *et al.* 1996). Women who are well informed are more likely to have more favourable outcomes including reduced psychological morbidity (Fallowfield *et al.* 1990), better psychological adjustment to diagnosis (Butow *et al.* 1996), strengthened self esteem (Kahane, 1993) and greater control in the decision making process (Siminoff, 1991).

A diagnosis of breast cancer can cause significant emotional distress, with estimates of anxiety disorders and depression in 30-45% of patients (Fallowfield *et al.* 1990; Kissane *et al.* 1998). Even in the absence of severe distress, breast cancer patients face considerable difficulties of adjustment. These include threats to integrity of body image and sense of attractiveness and femininity, sexual function disturbance (Turner *et al.* 1998) and awareness of a diagnosed malignancy and its continued threat to a woman's future (Ray, 1984).

The House of Representatives Standing Committee (1995) found that women with breast cancer rarely received the amount of support that they, or their families, required. Many women were unable to develop a rapport with their specialist, with doctors often unable to communicate on the patient's wavelength. Some doctors appear to have an inadequate understanding of the emotional and psychological needs of patients or to lack adequate communication skills. Ray and colleagues (1984) and Maguire (1986) suggest that doctors are ill-prepared by their training or experience to provide emotional support.

Generalist nurses have also been found to be ill-equipped for both detecting and dealing with psychological distress in women with breast cancer (Maguire *et al.* 1978) and more recently, in palliative care settings (Heaven *et al.* 1997*)*. Suominen et al (1995) found that breast cancer patients reported insufficient support during all phases of treatment, even though nurses felt they had provided a great deal of support. Although most nurses regard supportive care as an intrinsic component of their role, Ray and colleagues (1984) found that beyond the giving of comfort, nurses were more inclined to identify specialist nurses as the most appropriate professional to counsel breast cancer patients.

Development of specialist breast nurses

Specialist breast nurses (SBNs) have training and expertise in the management and treatment of breast cancer patients (MacMillan Cancer Relief, 1995). Since the 1970s, SBN positions in the United Kingdom (UK) have become well established as part of good practice in the management of women with breast cancer. SBNs see women at diagnosis and during the course of treatment to provide information, coordinate supportive care and to screen for the development of anxiety and depression (Jary and Franklin, 1996).

The SBN role has been extensively evaluated in both randomised control trials (RCTs) and descriptive studies. Table 1.1 summarises key findings from RCTs comparing SBN interventions with more routine care. The RCTs show that SBNs can enhance early recognition of social support needs and decrease psychosocial distress such as body image concerns and depression among women with breast cancer (McArdle *et al.* 1996; Watson *et al.* 1988). SBNs also increase early detection and referral for professional counselling of women with psychological morbidity (Maguire, 1980; Wilkinson *et al.* 1988).

In other RCTs, women with breast cancer who had the opportunity to have information clarified and reinforced by a SBN had increased levels of knowledge about treatment compared with women who did not have access to such a nurse (Clacey *et al.* 1988). The SBN's role in improving communication cannot be understated, as this is of major importance for women. Women may feel less constrained by time pressures with a nurse than with a doctor, and therefore may ask more questions. Allowing ample consultation time and providing good quality information have been identified as important factors in assisting patients in the decision making process (House of Representatives Standing Committee on Community Affairs, 1995).

The SBN's provision of continuity of care from diagnosis onwards is crucial for developing a trusting relationship with patients (Watson *et al.*1988). Providing ongoing support after the initial treatment phase may continue to benefit women. Palsson and Norberg (1995) found that continuous supportive nursing care which extends after the hospital stay can lead to feelings of security and an increased sense of control for women.

Despite the demonstrated benefits of SBN positions, a specific role definition for practising breast nurses remains absent. This is reflected in the tendency of descriptive studies to focus on only one aspect of the SBN role (Poole, 1996). Although the UK Royal College of Nursing has produced standards of care (Royal College of Nursing, 1994), the extent to which the standards are indicative of SBN roles is not known (Poole, 1996). Although SBNs are seen as primarily providing support and information during the acute stages of breast cancer in the UK, many SBNs perceive they have a wider responsibility in promoting improved quality of life for all patients (Jary and Franklin, 1996).

This lack of clear definition can fractionalise and marginalise the role of SBNs (White *et al.* 1997) and reduce the effectiveness of the care they provide. For example, although providing psychosocial care is seen as a key component of the SBN role, due to heavy caseloads specialist nurses are often reduced to providing crisis intervention for patients with clearly defined needs (McArdale *et al.* 1996). Tait (1995) found that only 40% of patients had a psychological assessment recorded in their records by specialist nurses.

Table 1.1: Summary of randomised control trials involving specialist breast nurses

Interventions trialled	**Results**	**Statement/s**	**Reference**
1. Practical & physical information; emotional support from breast nurse at diagnosis; pre & post surgery; home visit; 'on demand' versus 2. Standard care	(At 3 months) Intervention group less depressed ($p<0.05$), more personal control ($p<0.03$), increased vigour ($p<0.01$)	SBN can assist patients to adjust more rapidly in the year post surgery. Support from the time of diagnosis is important.	Watson *et al.* 1988
1. Support from breast nurse pre & post surgery; follow-up clinics versus 2. Standard care	(At 12-18 months after surgery) Counselling failed to prevent morbidity, but increased recognition & referral of psychiatric morbidity.	SBNs increase early recognition and referral of patients with psychological morbidity.	Maguire *et al.* 1980, 1983
1. Support from breast nurse or 2. Support from voluntary organisations or 3. Support from both or 4. Standard care. Duration determined by patient	(At 12 months) Scores of psychological morbidity significantly lower in patients receiving support from SBNs compared with other groups.	SBNs can significantly reduce psychological morbidity and psychosocial distress.	McArdle *et al.* 1996
1. Individual counselling by ward & community nurses, monthly for 3 months versus 2. Limited counselling by specialist nurse for 1-2 months post discharge versus 3. Unlimited counselling by specialist nurses bi-monthly for 1 year	(At 3 months) Counselling did not prevent psychological morbidity, but specialist nurses better than ward /district nurses in recognition & treatment of psychiatric problems.	SBNs are better than general nurses in detecting and referring women in need of psychological counselling.	Wilkinson *et al.* 1988
1. Counselling & education by specialist nurse in 3 x 45 minute sessions over 9 days post-operative versus 2. Same nurses gave information only in 3 x 20 minute sessions (over 9 days)	(At 4 months) No difference in depression or anxiety. (At 1 week) Counselled group was less depressed, with better knowledge of treatment & post mastectomy support services.	SBNs can increase a patient's knowledge of treatment and post-mastectomy support services, and reduce the initial level of depression.	Clacey *et al.* 1988

Advocates of "patient demand" led breast nurse interventions (Thomson 1996; Jary and Franklin, 1996) may be disadvantaging their patients, as Luker *et al.* (1996) found that patients in need of information did not feel that this justified initiating contact with the SBN. Furthermore, both nurses and patients have been reported to be unclear about the nurse's role in patient education (Palsson and Norberg 1995).

Specialist breast nurses in Australia

While there is growing interest in SBNs in Australia, there has been a lag in the development of positions and quality evaluations. There are a number of nurses who practise as breast support nurses as a variable percentage of their work (Neil, 1997). In a recent national survey of women diagnosed with early breast cancer (Williams *et al.* in review 2000) 47% of women reported no access to a SBN, and 25% saw a SBN only once. Of the 28% who had contact with a SBN on more than one occasion, only 14% received contact from diagnosis through to the post-operative period.

There is a considerable range in the knowledge and skills of practising SBNs, and no agreed standard of practice. In some cases, the SBN is a volunteer, while others have substantial ward duties other than the provision of information and supportive care (Webb and Koch, 1997).

In an attempt to define the current role of SBNs in Australia better, White and colleagues (1997) surveyed 16 SBNs who spent more than 70% of their work time caring for patients with breast disease. The SBNs were asked to identify and rank descriptors of their role. Consistent with international findings, SBNs perceived their role as primarily providing psychosocial support for patients with breast cancer, although some perceived the role to include all breast diseases. Unlike the UK model, however, only 56% of SBNs surveyed attributed importance to coordinating continuity of care for women with breast cancer. In addition, all the nurses perceived themselves as caregivers in relation to the physical needs of women with breast cancer, although the extent of this clinical role was highly variable.

Although the variability of SBNs' roles in Australia reflects the diversity of treatment and health care settings available, the common core components of the SBN role for Australian practice have not been explicitly defined. There is growing evidence that practice standardisation through the implementation of clinical guidelines decreases care fragmentation and promotes best practice standards (Grady and Wojner, 1996).

The SBN demonstration project therefore sought to:

- use evidence from previous research to constitute a SBN model of care;
- propose a protocol for observing the activities undertaken by SBNs;
- evaluate the feasibility of the model for Australian practice; and
- identify which factors need to be addressed to translate the model into routine Australian clinical practice.

Chapter 2: Project overview

Aims of the project

The benefit of specialist breast nurses (SBNs) in improving many aspects of supportive care has been demonstrated in randomised control trials. Despite this evidence, SBN positions remain relatively rare in Australia. This project, then, does not duplicate existing work by exploring whether SBNs could be effective under trial conditions, but rather explores the operation of these positions in Australia. The project was designed to collect information that might help hospitals considering establishing SBN positions to consider their likely benefits and costs, and the most appropriate approaches to establishing and resourcing them. The aims of the SBN demonstration project are to explore:

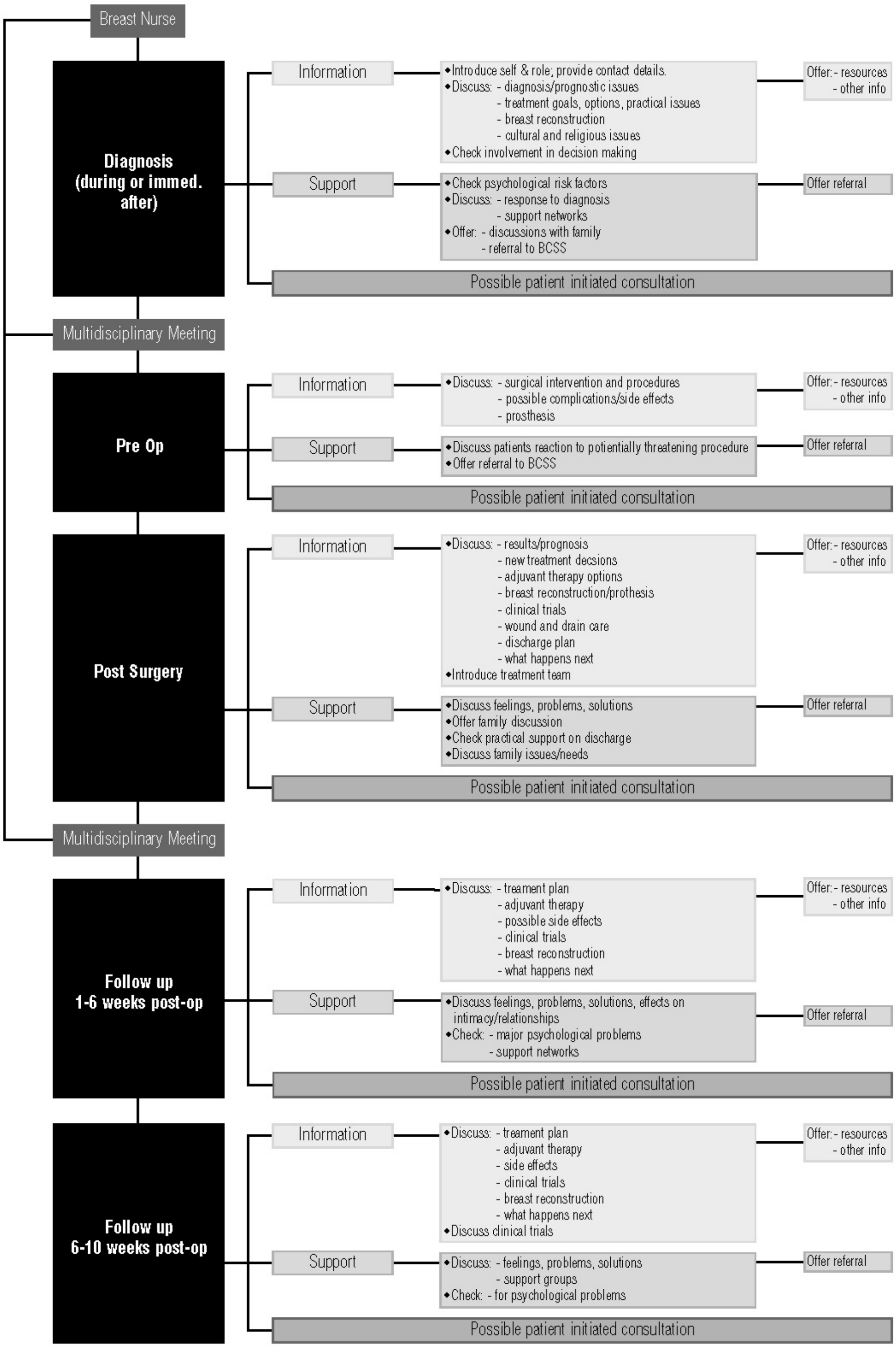
1. the tasks undertaken by SBNs and their requisite skills and expertise;
2. the acceptability of the SBN role within a multidisciplinary team;
3. the acceptability of the SBN to women with breast cancer;
4. SBNs' impact on information and support provision to women with breast cancer in Australia; and
5. the resource implications of SBN positions.

Specialist breast nurse protocol

A SBN model of care, which translated research findings and recommendations into a clinical pathway of intervention, was developed (Figure 2.1). The intervention was based on:

- *NHMRC Clinical practice guidelines for the management of early breast cancer (1995);*
- *NHMRC National Breast Cancer Centre's (NBCC's) draft Clinical practice guidelines for the management of advanced breast cancer (1998);*
- *NHMRC National Breast Cancer Centre's (NBCC's) Psychosocial clinical practice guidelines for providing information, support and counselling to women with breast cancer (NHMRC NBCC, 2000); and*
- practical advice from the breast nurses participating in the project (see Appendix 1 for summary of evidence).

Figure 2.1 Specialist breast nurse clinical pathway



The intervention was divided into five predetermined consultations linked with key treatment phases. The clinical pathway provided a checklist that the SBN would refer to while assessing a woman's individual needs. The intervention was tailored to meet those needs. Women were also able to initiate additional contact with the SBN at any time.

Project design

Four treatment centres were selected to participate in the project following a competitive bidding process. The treatment centres, referred to as the Collaborating Centres, are spread across Australia and represent a variety of treatment settings-including rural/urban and private/public health care settings.

Collaborating Centres

Although the chosen centres represent diverse service delivery, each met the following criteria:

- an evidence-based, multidisciplinary and consumer-oriented approach to the management of breast cancer;
- commitment to delivering care in accord with the *NHMRC Clinical practice guidelines for the management of early breast cancer* (1995), which includes ensuring that women are informed and actively participate in treatment decisions;
- recognition as peer leaders in breast cancer management; and
- evidence of networks with regional/rural centres for the provision of breast cancer services.

The Collaborating Centres were:

- Dubbo Base Hospital, New South Wales (NSW) – a rural hospital with a bed capacity of 170, which functions as the referral centre for the Macquarie, Castlereagh and Orana Area Health Services of NSW. The service area hosts a population of 115,000 and covers a land area of almost 200,000 square kilometres.
- Inner and Eastern Health Care Network, Victoria provides services to the inner and eastern areas of Melbourne, and services approximately 1.2 million people. Participating hospitals within the network were the Alfred Hospital, Maroondah Hospital and the Peter MacCallum Cancer

Institute. In addition, a surgeon with visiting rights to Mitcham and Ringwood Private Hospitals also participated in the project.

- The Royal Adelaide Hospital, South Australia (SA) – encompasses a comprehensive cancer centre which provides the only public hospital radiation oncology facility for SA (1.4 million people), as well as serving the Northern Territory and Broken Hill. Women with breast cancer are seen in a purpose-built women's health centre.
- The Royal Perth Hospital, Western Australia – one of three breast assessment centres servicing the entire State, extending its support to most regional areas including the remote north-west.

Appendix 2 supplies codes used for each Collaborating Centre in this report.

Participating specialist breast nurses

Seven nurses were trained to implement the SBN model of care. Four of the six public hospitals involved in the project employed a SBN on a full-time basis. One hospital employed two part-time SBNs (job-sharing), although one of the nurses had a more predominant role (34 hours per week), while the other nurse mainly provided backup support during busy clinic days as part of the project. The remaining public hospital employed a SBN on a part-time basis, reflecting the smaller numbers of women presenting to that centre. Finally, a SBN was employed on a part-time basis by a surgeon to provide care to patients both in his rooms and the private sector.

All the nurses had previous clinical experience in oncology and had held senior nursing positions (Appendix 3). Two nurses were already established in breast nurse positions at their centres, while the remainder were newly appointed.

Participating women with breast cancer

Ethical approval was obtained from each Collaborating Centre’s ethics committee.

Eligibility

Women were considered eligible to participate in the demonstration project if:

- they had a new diagnosis of early or locally advanced breast cancer or a new diagnosis of a local recurrence of breast cancer;
- they were aged over 18 years; and

- they spoke and understood English sufficiently to complete the evaluation questionnaires.

Recruitment procedure

Eligible women who presented at any of the Collaborating Centres between March and September 1998 were invited to participate. They were given an information sheet explaining the SBN intervention and the evaluation procedures to be undertaken, and asked to sign a consent form (Appendix 4).

Both the information sheet and consent form assured women of the anonymity of their responses. Evaluation questionnaires sent to the women were clearly identifiable as correspondence from the NBCC, as were the reply-paid envelopes, thus emphasising that women's responses could in no way compromise their relationship with any member of their treatment team. Treatment team members were blind to individuals' responses.

Consenting women were given the option of having their consultations audio-taped. Although the primary purpose of taping consultations was to provide women participating in the study with an additional information resource, women were also asked if they would be willing to lend their taped consultations to the NBCC towards the end of their treatment. Women who indicated they did not want to lend their tape/s were not excluded from the study.

Response rate

Of the 272 women who were identified by SBNs as eligible to participate, a total of 240 women (88%) consented to take part in the project. The numbers recruited from each Collaborating Centre are shown in Appendix 5. The number of women seen by the SBN but considered ineligible or who declined to participate in the project is shown in Appendix 6. The socio-demographic characteristics of women receiving the SBN model of care are shown in Appendix 7.

Overview of chapters

Chapter 3: Implementing the SBN model

This chapter describes the preparation undertaken by SBNs and Collaborating Centre project teams for this project. During the implementation of the SBN model, the seven participating SBNs were in regular contact with the project coordinator, in order to discuss and deal with any issues arising. Common experiences are also recorded in this chapter.

Chapter 4: What do SBNs do?

Although the clinical pathway gives guidelines for the intervention provided by SBNs, it is necessary to analyse in detail what the SBNs in this project did on a daily basis. For this reason, SBNs completed a day log detailing their clinical and non-clinical activities during their working day. The logs were completed for one week a month, for six months.

A patient log was also kept for each woman recruited to the project. In this, SBNs recorded demographic details, treatment undertaken, psychological risk factors and details of all their interactions with the patient and family. This chapter examines what SBNs did with women in the project, and what their daily activities were.

Chapter 5: How the treatment team and SBNs view the SBN role

To be successful, the SBN model must be understood and accepted within the multidisciplinary team. This chapter reports the perceptions of treatment team members, allied health professionals, the Breast Cancer Support Service (BCSS) volunteers, and participating SBNs. These perceptions were assessed at the end of the project by means of a semi-structured telephone survey conducted by independent interviewers.

Chapter 6: Women's perceptions of the SBN role

Women participating in the study were contacted at two and six months after diagnosis to assess their contact with, and satisfaction with the care provided by, the SBN. They completed a self-administered questionnaire and returned it to the NBCC in a reply paid envelope. This chapter reports on this data.

Chapter 7: The impact of the SBN on women's perceptions of care

The impact of the SBN model on women's perceptions of care was assessed six to twelve months after diagnosis using a previously validated interview schedule, the National Consumer Survey (Williams *et al.* in review 2000). This was conducted as a telephone interview administered by an external research agency, using a computer assisted telephone interview system.

Responses of women receiving the SBN intervention were compared to those of women from a nationally representative sample of women with early breast cancer (referred to as the national control). This comparison does not control for potential differences already existing between the Collaborating Centres and other treatment centres in Australia in terms of other aspects of care (ie other than the breast nurse). Women's responses were therefore also compared with a sample of women treated for breast cancer at the Collaborating Centres prior to the introduction of the SBN intervention (referred to as the retrospective control) (Figure 2.2). This allowed the Collaborating Centres to be compared with the national average before the introduction of the SBN model. Furthermore, site differences could be controlled for, by evaluating women's satisfaction pre and post SBN intervention at the Collaborating Centres.

Chapter 8: The nature and impact of SBNs' psychological care

One of the core tasks of the SBN is to assess women's psychological needs and to adjust their intervention accordingly, in an attempt to reduce levels of psychological morbidity in women with breast cancer. In particular, SBNs should refer women with significant psychological problems to appropriate health professionals. The impact of the SBN model on the emotional wellbeing of women in this project was assessed at two and six months after diagnosis using the self-administered General Health Questionnaire – 12 (GHQ-12) (Goldberg *et al.* 1988), which was mailed with the satisfaction questionnaire. This chapter analyses the outcomes of SBNs' psychological treatment of women in the project.

Chapter 9: Evaluating the economic feasibility of the SBN role

Key factors to be considered when examining the economic feasibility of the SBN role were also investigated in this project. A case study exploring the impact of the SBN on resource use within the multidisciplinary team was conducted in one participating breast clinic, and is reported here.

Chapter 10: Feasibility of the evidence-based SBN model of care

This final chapter examines issues affecting the translation of the SBN model of care into Australian practice. Three key issues are examined: skills needed by SBNs; sustainable caseloads; and the ongoing support needs of SBNs.

Chapter 3: Implementing the specialist breast nurse model

This chapter defines the ideal role of a specialist breast nurse (SBN) and describes how the breast nurses were prepared for this position. Transcripts from discussions with the nurses during the six months they implemented the model are analysed. The chapter also examines issues that emerged for the SBNs while they introduced the role, and how the model worked in practice.

Defining the specialist breast nurse role

The evidence-based SBN model provides a structured approach to the provision of clinical and supportive care by way of a clinical pathway (Figure 2.1). The pathway guides SBNs in their assessment and response to women's needs for information, practical assistance, emotional and psychological support, and promotes awareness of cultural and spiritual beliefs that may affect a woman's response to breast cancer. To help SBNs implement the clinical pathway, core activities of the SBN role, applicable across all treatment centres, were identified.

Core activities of the specialist breast nurse role

The core activities of the SBN role are to:

- provide supportive care to women diagnosed with breast cancer (early through to advanced); and
- ensure continuity of care for these women (from diagnosis to follow-up after treatment).

Specifically these activities include:

- providing and clarifying information regarding psychosocial, physical, treatment, practical, cultural and communication issues;
- providing clinical information regarding such issues as wound care and complication prevention;
- providing supportive counselling when needed, including family, sexuality and grief issues;
- liaising with, and referring women to, other health professionals; and

- ensuring early recognition and referral of women with significant psychological problems to appropriate health care professionals.

Site-dependent peripheral activities

As described in Chapter 2, the Collaborating Centres represent a diverse range of treatment settings and service delivery across Australia. This diversity is reflected to some extent in the extension of the SBN role to meet the needs of particular hospitals. In order to successfully carry out the core activities and meet the specific requirements of their role within the hospital, SBNs engaged in a number of peripheral activities, including:

- clinical procedures in relation to breast cancer patients such as wound dressings, removal of drainage tubes and seroma aspiration;
- involvement in support groups;
- attending multidisciplinary meetings;
- administrative activities;
- educating other health professionals;
- attending educational meetings for career development;
- attending debriefing sessions; and
- participating in committees.

Types of patients

The SBN focuses on providing care to women diagnosed with breast cancer. To a lesser extent, she may see other types of patients, including those:

- at the pre-diagnostic stage;
- with benign disease;
- receiving palliative care for systemic breast cancer;
- with cancer other than in the breast;
- with a family history of breast cancer;
- undergoing other breast surgery; and
- who were previously treated for breast cancer and continue to receive follow-up care.

Preparing the specialist breast nurse

A number of programs were conducted to ensure that the nurses participating in the project had comparable skills and current knowledge of the treatment and management of breast cancer (Table 3.1).

Implementing the SBN model

On commencement of the project, the SBNs sent introductory letters to, or spoke directly with, treatment team members and other allied health professionals about the project, their role, and how it would be evaluated. Brochures promoting the service provided by the SBN were circulated by some of the nurses, and in-services were given.

Method

Evaluation of the implementation process – including the identification of issues for the SBNs in adhering to the protocol, and the responses of the multidisciplinary teams to the SBN intervention – was based on observational data extracted from:

- individual teleconferences with each Collaborating Centre prior to commencement of the SBN intervention;
- bi-monthly teleconferences involving all Collaborating Centre team members and the NBCC project team;
- monthly teleconferences involving the NBCC Project coordinator and all SBNs; and
- weekly telephone contact between the NBCC Project coordinator and each SBN.

The Project coordinator reviewed transcripts of, and minutes from, the teleconferences and telephone conversations in order to identify key issues and concerns raised by SBNs and project team members. Quotes in the following text were extracted from these transcripts.

Initial responses to the model

Prior to being implemented, the SBN role was discussed with each of the Collaborating Centres' project team in separate teleconferences. Although the model was generally met with enthusiasm, it was important to work through the clinical pathway with each centre, and determine how the model could best be adapted to meet that centre's specific needs. For instance, one centre wanted to ensure that the model accommodated women treated at more than one site, as this was a common occurrence.

Table 3.1: Preparing the nurse for the SBN role

Event	Objective
SBN 2-day workshop	• discuss integration of evidence-based guidelines into SBN model of care • develop strategies for implementing model • improve supportive counselling skills • network with other SBNs • develop a library of National and State resources for women with breast cancer and their families • familiarise SBNs with research and documentation procedures of project
Communication skills training – two day workshop with medical members of the treatment team	• discuss integration of evidence-based guidelines in the provision of supportive care • interactive training in effective communication skills • gain experience in dealing with difficult situations
Periodic literature review updates	• promote awareness of current research and literature on issues relevant to breast nursing
Monthly teleconferences with Project coordinator	• discussion and resolution of issues associated with implementing the SBN model • supervision and progress update by Project coordinator • networking and support among SBNs
Regular phone contact with Project coordinator	• individual supervision focusing on specific issues associated with each Collaborating Centre

Issues emerging during the initial teleconferences with each centre prior to implementing the model included the following:

Issue:
The content of information provided by SBNs, particularly at diagnosis, was an issue for some clinicians (see Chapter 5 for more details). This was more evident when the nurse had been newly appointed and the clinician was unsure of her skills and expertise. A major concern was that the nurse might provide contradictory information to that of the surgeon, or raise issues that the surgeon may not necessarily have wanted raised. Discussing prognostic issues was highlighted as a concern for many centres.

Response:
It was important to discuss the SBN's role and elaborate clinical pathway details with treatment team members. Ideally, SBNs are in a position to clarify and reinforce information provided by clinicians, to provide additional information tailored to the woman's needs and to offer support. Discussing prognostic issues (such as when a woman can expect to be told her prognosis) has been found to be an important discussion point for many women during their first SBN consultation (Appendix 1).

Issue:
Another issue was the boundaries of the SBN role and possible overlap with other health professionals and community support organisations (see Chapter 5 for more details).

Response:
To address this, SBNs negotiated the boundaries of their roles with other team members. For the newly appointed SBNs, negotiating their role was assisted by the availability of an explicit role definition and the clinical pathway.

In centres that already had established breast nurse positions in place, it was important to compare the new SBN model and the breast nurse's prior role, in order to ensure emphasis on the support and counselling aspects of the SBN role.

Issues encountered by SBNs while implementing the model

Adhering to the clinical pathway

The SBNs experienced some difficulties seeing women face-to-face at the five specified times. As illustrated below, the timing of each consultation was dependent on the existing structural set-up for service delivery at each treatment centre.

Diagnosis:
In the absence of a formal diagnostic clinic, some SBNs reported experiencing problems receiving referrals for newly diagnosed women. For instance, if the patient was seen privately by a surgeon, often the first contact with the SBN would not be until after admission for surgery. In the centres with a diagnostic clinic, the SBN was available to provide support while news of breast cancer was given.

Pre-operatively:
Some SBNs reported difficulties in seeing women pre-operatively. At some centres women attended a pre-admission clinic for their pre-surgical tests and examinations. They would then be admitted for same-day surgery, leaving a tighter time frame for the SBN to conduct the pre-operative consultation.

Post-operatively:
Most centres offered an early discharge program where women could be discharged within 48 hours after surgery and followed up by a hospital-based home nursing or community nursing service. This meant that there was a shorter time frame for SBNs to see women prior to discharge, especially if they were discharged on a weekend.

Follow-up 2 (6-10 weeks post-operatively):
The timing of the final consultation could also pose a problem. Some women had already returned to their rural residence, others were back at work and/or busy undergoing radiotherapy or chemotherapy.

If it was logistically difficult to see the woman face-to-face for any scheduled consultation, the SBN would attempt to conduct the consultation by telephone. SBNs reported that this enabled them to continue to support the woman, and that it could be as beneficial as face-to-face contact.

> **SBN:** I did a lot of phoning of patients when they had gone home … because they had so many different appointments, I would often just ring them ... [T]hey were so pleased to have a call and they were often feeling a bit depressed and a lot of social support [was] withdrawn and they may perhaps not have had the energy if depressed, or motivation, to make the contact to reach out to you.

However, quality of care may be affected if the number of phone consultations is disproportionately greater than face-to-face contact. For instance, at one centre the SBN attended the diagnostic clinic at a neighbouring hospital and saw women at diagnosis only. The remaining consultations were all conducted by phone. The SBN believed the care she provided to these patients was qualitatively different from the support given to other women in the project. Patient feedback also suggested that women who had limited face-to-face contact did not experience the same continuity of care (Chapter 6).

In the event that a woman failed to respond to the follow-up visit/s, a letter was sent which acknowledged the SBN's attempt to make contact and stated the SBN's availability if ever the woman wanted to initiate further contact.

In summary, the SBNs agreed that although coordinating multiple contacts for each woman was time-consuming, most women benefited from the extra contact. There were many instances where the SBN believed that a woman would not have received enough support if it had been left to her to initiate contact with the SBN. Women who did not want ongoing support from the SBN after discharge from hospital typically cancelled their follow-up appointments, but were made aware of the SBN's availability.

An increased workload

Workload was a major issue for all SBNs. This was attributed to multiple factors.

(i) There was an increase in the number of consultations with women. Although many SBNs initially felt that the model was comparable with the care they were already providing women, feedback during the project confirmed that the protocol increased their frequency of contact with women.

> **SBN:** I'm seeing the women more times. A lot of women who seem to be going OK and haven't contacted me, I would have allowed them to go through the system because I have other priorities at this time … In the past, these women would only get my assistance if they contacted me.

(ii) Consultations were more structured and took longer because they covered a wider range of topics.

> **SBN:** When I sit down with a woman, I'm spending a great deal of time … When I saw them [in the past] in little sharp bursts, it was more [on a] needs basis.

(iii) There was a cumulative load of patients being actively followed up over the course of the project. This was due to the SBNs following women up to 10 weeks post-operatively while simultaneously taking on newly diagnosed patients.

> **SBN:** This week has been dreadful for me because I have a couple of newly diagnosed young women at the same time as five in hospital and all these follow-ups.

(iv) The SBNs found it difficult to 'off-load' some peripheral activities that had been part of their previous role.

> **SBN:** I cannot put off my support groups … I have tried to find someone else to do it. If I don't do it, the support group does not go on.

Adding to the demanding workload was the project documentation component of the role, which was extensive. The SBNs reported a shift in activities over the course of the project (Chapter 4). They devoted less time to either peripheral activities or patients with a diagnosis other than breast cancer, although this could also be a source of personal strain.

> **SBN:** In my role before, I actually saw a lot of people who didn't have breast cancer. They were having breast reconstruction or had benign disease and I actually found it a balance. But now I'm virtually only seeing people in this study and I'm finding it an absolute drain as I don't have the balance of that lighter, benign stuff.

There was little opportunity for the SBNs to attend formal debriefing sessions, although some SBNs were able to meet with other breast nurses in their own time on a monthly basis (Chapter 10).

Contact with members of the multidisciplinary team

Many SBNs reported that the clinical pathway encouraged greater contact with treatment team members (Chapter 5). They felt that this not only enhanced communication between team members but also served to strengthen these relationships.

Additionally, some SBNs noted that the model facilitated new opportunities for extending their network with other health professionals.

> **SBN**: [The clinical pathway] allowed me to develop new contacts with the plastic surgeons and specialist plastic nurses. I was able to support women during their consultations with plastic surgeons [for reconstruction surgery]. The plastic surgeons became aware that we were counselling women and giving them information, and [women] were better prepared for reconstruction surgery.

Implementing the model across multiple sites

There was favourable feedback from two SBNs who referred women to each other. Women were initially seen by the SBN in the surgeon's private rooms before undergoing treatment. The same nurse would continue to provide support while the patient was treated privately. If the patient needed treatment from a public hospital which was participating in the project, the follow-up care would be provided by the SBN from that hospital. The SBNs reported that consistency of care was maintained, the transition for women across hospitals appeared to be smoother and women were less likely to become "lost in the system".

> **SBN**: [I]t is an interesting process to let women know that another SBN will be doing *X* and *Y* at a certain point.

There were also reported benefits for women who received treatment in both the public and private sectors:

> **SBN:** Actually it's good for me to have the public sector backup and resources that often aren't in the private sector.

Conclusion

Although the SBNs did not initially feel that the model was dissimilar to the care they already provided, implementing the model proved otherwise. In order to provide more comprehensive care to women with breast cancer they needed to re-negotiate their role. While the clinical pathway establishes a framework for providing continuity of care, it needs to be flexible enough to work within different settings.

Chapter 4: What do specialist breast nurses do?

Introduction

The specialist breast nurse (SBN) role has not been well defined in Australia, and variability in the role is evident across different settings (White *et al.* 1997). While the clinical pathway provides a model for SBNs' activities, the extent to which this is translated into daily clinical practice needs to be systematically assessed. This chapter examines what the SBNs in this project did on a daily basis. Details are given of the time spent on clinical and non-clinical activities. The changing needs of women at different treatment phases and the types of intervention made by SBNs are also described.

Method

Throughout the study, SBNs maintained detailed records of their daily activities (day logs) and interactions with each woman (patient logs). At the outset of the project, SBNs were asked to identify the type of daily activities they performed. A day log was constructed to include the activities agreed upon by the SBNs, then piloted and revised.

In the day logs, SBNs documented what they did clinically (including number of women seen) and non-clinically (for example, conducting inservices), and the time spent on each activity. Day logs were filled out for an entire week once a month over a six-month period (except for the SBN in the private clinic, who started data collection later and so only collected data for a three-month period). Overall, 195 days of data were collected.

The patient logs are a detailed record of all consultations between the SBNs and each woman. Consultations were categorised as either nurse-initiated (the five scheduled consultations) or patient-initiated. The SBNs documented the woman's information needs, physical and psychological concerns, familial, cultural and religious needs, and the intervention they provided. Women's needs were recorded in the patient logs as free responses by the SBN and were subsequently coded into

21 categories developed in previous research studies (Cancer Research Campaign, 1994). The types of resources and referrals provided were coded at the time of log entry. Interventions were recorded in the logs as free responses, and later coded as "providing information", "supportive counselling", "treatment" or "liaison".

Analysis of data

All data analyses of the day and patient logs were conducted using the Statistical Analysis System (SAS).

Data from the day logs were examined to determine the proportion of time spent by SBNs on different activities at each treatment centre. The trends over time in the number of women seen by SBNs, the number of working hours per week, and the time spent on clinical activities per woman were calculated.

The patient logs were analysed to summarise each woman's assessed needs and the resources and intervention provided by SBNs. For each treatment phase, the proportion of women receiving consultations, referrals or resources, and the needs identified by the SBNs, were calculated.

Reliability of patient logs

A sample of taped consultations from each treatment phase was used to assess the reliability of the SBNs' records in the patient logs. Two coders conducted the reliability checks, and met to ensure agreement regarding codes. One coder then coded all the tapes (n=18) and compared her coding with that of the SBN. Analyses of coding indicated substantial agreement between the SBNs' records and the coder's tape coding at three treatment phases (pre-operative and follow-ups 1 and 2). At diagnosis and post-operatively, SBNs recorded more discussion and interventions than were recorded on the audiotape. This may have been due to SBNs providing additional printed materials (which would not be evident on the tape) and/or to faulty recording.

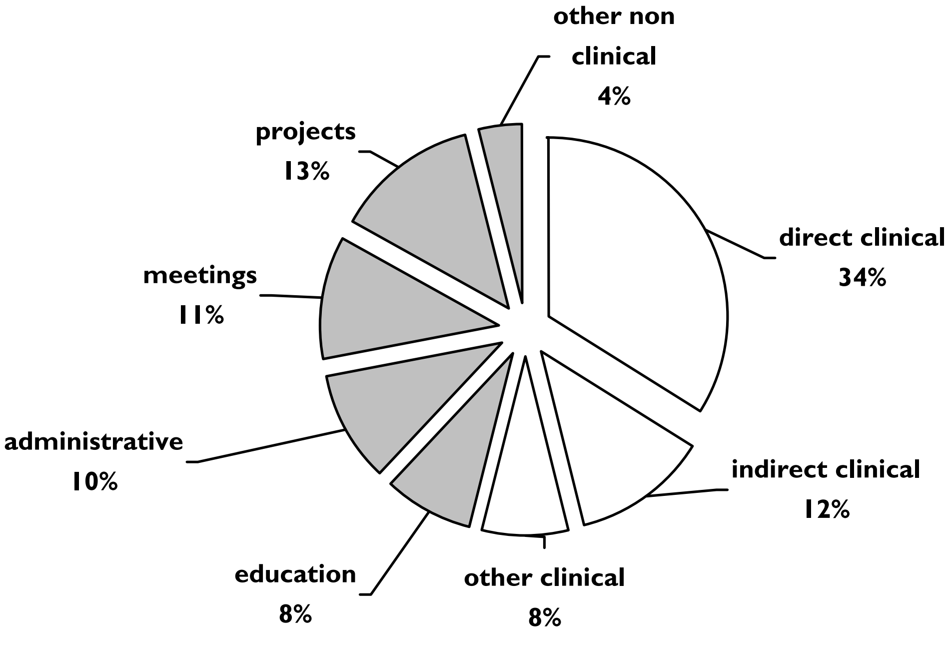
Results

SBNs' daily activities

SBNs' daily activities are summarised in Table 3. Note that "administration" includes many project and patient-related activities such as preparing information packs, photocopying, answering mail, completing forms and making phone calls and faxes. 'Education' includes giving seminars, presentations and inservices, acting as preceptors, attending lectures, reading journal articles and undertaking tertiary level study.

SBNs were involved in direct and indirect clinical activities on a daily basis. However, non-clinical and other activities-such as multi-disciplinary meetings, patient support groups or informal patient contacts-were not undertaken daily. The frequency and time spent on non-daily basis activities are summarised in Appendix 8. In describing how SBNs spent their time per day, time spent on non-daily basis activities was averaged over the days, as summarised in Figure 4.1 (and detailed in Appendix 9).

Figure 4.1: Specialist breast nurses' time spent on activities, per day



Time spent on activities

On average, the proportion of SBNs' time spent per day on clinical activities was 54%. Most of this time was spent on face-to-face contact with patients (20%), documentation (7%) and telephone contact (4%). On average, SBNs worked 7.6 hours per day and spent 4.1 hours on clinical activities. Most of the 46% of time spent on non-clinical activities was spent on activities related to this project (11%), administration (10%) and teaching (5%). There were some marked differences between centres in the proportion of time dedicated to clinical activities (Appendix 10). While the private nurse spent 84% of her time on clinical activities, this figure at the rural centre was 34%.

Caseload

Types of patients seen

Overall, more than two-thirds (69%) of the women seen by SBNs had breast cancer (Appendix 11). At most centres more than 75% of consultations with the SBNs involved women with breast cancer (Appendix 12) and over 85% of the SBNs' clinical time was spent on women with breast cancer (Appendix 13). At site D1, the higher proportion of individuals with cancer other than in the breast seen by the SBN was accounted for by the SBN's half time allocation to the SBN project (her remaining time was allocated to non-breast cancer patients).

Trends over time

From March to August, the number of patients seen by SBNs increased gradually (from 25 to 35 women per week), as did the number of working hours (from 32 to 38 hours per week) (Appendix 14). The time spent on direct and indirect clinical activities per woman was greater for those with breast cancer (range: 33-39 minutes) than for those without (range: 19-28 minutes) (Appendix 14).

SBNs' consultation with women

The SBNs initiated consultations and contacted women in the project either face-to-face or by telephone. During the diagnosis phase, 61% of the 237 women in the study received at least one nurse-initiated consultation (Appendix 15). The proportion of women receiving a nurse-initiated consultation was over 93% for each of the other treatment phases. The main mode of contact was face-to-face. Women could also initiate consultations and contact SBNs, either face-to-face or by telephone. The proportion of women initiating an additional consultation increased from the pre-operative phase (5%) to follow-up 1 phase (31%) (Appendix 16). The main mode of contact was by telephone.

Among the women who initiated additional consultations, the majority (65%) had one consultation during a key treatment phase and 31% initiated two or three consultations (Appendix 17). For nurse-initiated consultations, SBNs spent on average one hour on a face-to-face consultation, and 20-30 minutes for a telephone consultation during most of the key treatment phases (Appendix 18). For patient-initiated consultations, SBNs spent on average about 30 minutes on face-to-face consultations, and 12-17 minutes for telephone consultations over the five phases (Appendix 19).

The project protocol of a 12-week relationship between women and the SBNs was also examined. We calculated the length of time for each woman from her first to last contact with the SBN. For the 39% of women who had no consultation in the diagnosis phase, we added 8 days to their time, as this was the mean interval from diagnosis to pre-operative phase for the other 61%. We found that 68% of women had contact with the SBN over 12 weeks or less and 91% had their last visit within 16 weeks (Appendix 20).

Identified needs of women

The needs of women were recorded by the SBNs and coded into the 21 categories reported in Appendix 21. Needs were coded within six content areas: cancer, health, treatment, psychological, social and practical problems and other. Specific subcategories were used to differentiate the type of need.

The nature of women's needs changed over the treatment phases. During the diagnosis and pre-operative phases, women were most frequently found to have their needs coded as "psychological symptoms" (25%, 51%) and "surgery" (30%, 53%). During the post-operative phase, the main needs were coded as "psychological symptoms" (52%) and "general treatment information" (45%). For the phases of follow-ups 1 and 2, the most frequently coded needs were "psychological symptoms" (49%, 40%) and "problems after treatment" (34%, 22%).

SBN intervention

Information giving

During the pre-operative, post-operative and follow-up 1 phases, information giving was the main intervention in 80% of cases (Appendix 22). The majority (81%) of women having a nurse-initiated consultation at diagnosis received one to ten resources (Appendix 23).

Counselling

Counselling included talking with the woman about her concerns and feelings, assisting with problem solving and decision-making, as well as discussing coping mechanisms, ways to relax, and providing appropriate reassurance. During the diagnosis phase, 33% of women received counselling from SBNs. At least 65% of women received counselling during each of the other key treatment phases (Appendix 22).

Treatment

During the consultations, SBNs treated women's clinical problems. This included wound-checking, discussion of wound care, demonstrating arm exercises, checking for lymphoedema, and education on lymphoedema and arm care. Women received treatment mainly during the post-operative (12% of women) and follow-up 1 (19%) phases (Appendix 22).

Liaison /referrals

The SBNs recorded whether they consulted with another health professional about a woman's needs and/or organised a referral. The frequency of a liaison intervention is reported in Appendix 22. Referrals organised by SBNs are reported by type of practitioner in Appendix 24. During the post-operative phase, the majority of referrals were made to physiotherapists (38%), community nurses (27%) or BCSS (24%). About 3% of women were referred to psychologists during the pre-operative phase and follow-ups 1 and 2, and about 1% was referred to psychiatrists during the post-operative phase.

Discussion

In this project, SBNs spent almost half (46%) of their time on non-clinical activities, including 11% on this project. At project completion, then, the SBNs would have freed up time. Almost three-quarters of consultations with SBNs involved women with breast cancer. Since the time spent on direct and indirect clinical activities remained constant, as the number of women seen by SBNs increased the number of working hours also increased.

Continuity of care provided by SBNs to women with breast cancer was observed in this project. Over 93% of women received a nurse-initiated consultation during most treatment phases. During the diagnosis phase, some women were difficult to contact, particularly if there was no diagnostic clinic, so only 61% of women received a nurse-initiated consultation. During the first follow-up phase (follow-up 1), almost a third of women initiated an additional consultation with SBNs, mainly by telephone. It may be beneficial to women with breast cancer if SBNs initiated an extra telephone consultation during this phase. Moreover, it appeared that a 12-week relationship between women and the SBNs was not long enough, as almost a third of women required more than 12 weeks. It may be better to plan for at least a 16-week relationship between women and the SBNs.

During the diagnosis and pre-operative phases, SBNs primarily provided women with information. Over the five treatment phases, psychological symptoms are major concerns for women with breast cancer, so providing psychological care is important. Providing care and referrals to deal with women's physical symptoms and problems after treatment is also important. The majority of women received treatment and referrals during post-operative and follow-up phases. The main referral agents were physiotherapists, community nurses and the BCSS. Providing information, counselling, treatment and referrals for women with breast cancer are therefore essential activities for SBNs.

Chapter 5: How the treatment team and specialist breast nurses view the specialist breast nurse role

Introduction

The role of the specialist breast nurse (SBN) is best understood within the context of the multidisciplinary team. While the role is distinct and unique, it entails considerable interaction and some degree of overlap with the roles of other health professionals and volunteers involved in the care of women with breast cancer. A significant component of the SBN role involves coordination and liaison with other treatment team members. As will become clear in this chapter, SBNs are highly valued within the treatment teams involved in this project precisely because of their ability to move between members of the team, and between women (and their families and friends) and the team. Such movement, which often takes place across different physical locations, is valued as an information sharing system which allows all members of the treatment team to maintain significant levels of knowledge regarding the individual women's progress, needs and concerns.

> **Surgeon**: I think the breast nurse specialist is an essential component of a multidisciplinary team. They really add a lot to … the care of the patient, particularly with the provision of information. I think they also enhance the process within the Clinic. They also enhance the whole multidisciplinary team by acting as a common link between the members and the patient as their advocate as well.
>
> **SBN**: We couldn't actually function if we didn't gain recognition from the multidisciplinary team.

This chapter examines how the full range of the treatment team and Breast Cancer Support Service (BCSS) volunteers viewed the SBN role performed within this study. Such an examination is essential: unless the SBN role is both well understood and well received by the full range of treatment team members, SBNs will not be able to provide women with the continuity of care that is recognised to improve health outcomes. The views of SBNs working in this project are also explored, including the nurses' descriptions of the main factors contributing to the success of the SBN role in Australian clinical practice, and concerns raised regarding the role.

Method

SBNs identified the frequency of contact they had with members of the treatment team and BCSS volunteers. A sample of up to 12 of these were contacted from each site and asked to participate in an interview. Fifty-three health professionals and BCSS volunteers as well as seven participating SBNs were interviewed by telephone about their views of the SBN model. Appendix 25 describes the sample interviewed. Five SBNs also took part in a face-to-face focus group discussion.

Two independent interviewers conducted semi-structured telephone interviews of approximately 45 minutes duration. They collected both quantitative and qualitative data regarding the interviewees' views of the SBN model. Questions were asked regarding both the model in a more abstract sense-an imagined, ideal situation, and its translation into practice within the interviewee's actual local situation. Although interviews with SBNs differed from those with other treatment team members, similar issues were covered in both, with many questions being identical. In one case, a SBN was partially re-interviewed by one of the authors, due to a technical failure of audio-recording in the original interview.

Interviewees were questioned about their perceptions of six areas:

- the level of contact with the SBN, and perceptions of any change in her role over the last year;
- key aspects of the SBN role, and the relative importance of her consultations with women at different treatment phases;
- role overlap between the SBN and other treatment team members, and how any role overlap was handled;
- the SBN as part of the multidisciplinary team at the interviewee's treatment centre-including the SBN's caseload, resourcing, availability and skills, and utilisation of the SBN by treatment team members;
- the SBN's actual skills and training, and views regarding their ideal training and skills; and

- the benefits and disadvantages to women, their families, members of the treatment team and the treatment centre of having contact with, or employing, a SBN.

In the SBN interviews, questions were also asked regarding:

- perceived differences between care for women using the structured model of this project, and previous care;
- the impact of the model on job satisfaction and utilisation of time;
- debriefing and professional support; and
- role renegotiation with other health professionals.

Interviews were audio-taped and qualitative data was transcribed verbatim and entered into a qualitative data analysis programme, The Ethnograph V4.0. The data was coded and sorted for recurring categories. Quantitative data was coded and analysed using The Statistical Package for the Social Sciences, version 8 for Windows (SPSS).

After the interviews were completed, a 90-minute focus group was run with five SBNs to clarify and discuss issues raised in the interviews. One SBN from each centre was present (two from Centre D), and the session was facilitated by the authors. This session was also audio-taped, transcribed and entered into The Ethnograph program. Again, transcripts were analysed for recurrent issues and concerns.

Core components of the role

Each participant was asked early in the interview to describe the key aspects of the SBN role. Overall, 26 categories of responses were recorded, with the most frequently mentioned being “providing information to women”, “providing supportive counselling to women”, “liaising and referring to other health professionals”, and “providing continuity of care”. Many respondents answered this question in a procedural manner (describing the SBN’s interactions as they would occur with a woman, in sequence), indicating a strong emphasis on the continuity of care aspect of the role. Table 5.1 gives the three most frequent responses within each professional group: specialist medical professionals (surgeons, oncologists and registrars); SBNs; nurses other than SBNs; community health professionals (GPs and community nurses); allied health (psychologists, counsellors, physiotherapists, and social workers); and BCSS volunteers.

In the qualitative data, the main emphasis in relation to core components of the role was on the SBN as a pivot or lynchpin of the treatment team. This related to the perception of the SBN as a conduit of information from women consumers to treatment team members (the SBN conveys information about the women to others), and from the treatment team to the women (the SBN reinforces information given by the treatment team to women). The SBN also functions as a conduit of information between members of the team (she lets members of the team know what has happened to women within other areas of the hospital and during other treatment modalities). Thus, as the quotes below demonstrate, she facilitates information sharing and knowledge of each patient's progress and needs within the treatment team. This important aspect of the SBN role occurs in many different modalities, ranging from formal multidisciplinary team meetings to less formal discussions with individual team members. The perception (described in more detail below) that, as specialist nurses, SBNs gain access to different information from women is significant here. It is a commonly held perception that the SBN's emphasis on support and holistic care of the individual woman means that she feels comfortable in sharing feelings and information with the SBN which she may not bring up with other treatment team members.

> **Radiation oncologist**: From the medical perspective, it's someone who's there to provide information to … us, in terms of what's happened beforehand, why there's some hold-up in a particular treatment [so] that the patient hasn't come on to the next stage. Or they act as a coordinator for the medical people looking after the patient as well. A link person between the various medical specialists too.
>
> **Interviewer:** Do you think that the breast nurse role benefits other members of the treatment team, allied health or support services?
>
> **Social worker**: I think so, yes … Because it gives them a greater insight into the patients … They are better informed as to the dynamics of that person and how they might cope with diagnosis and treatment. It gives them reassurance that the person is getting support.

Table 5.1: Perceptions of key components of the SBN role: ranking of response, by professional group

	Professional group					
Rank	**Specialist medical professionals**	**SBNs**	**Nurses other than SBNs**	**Community health professionals**	**Allied health**	**BCSS volunteers**
1st	Information Support	Information	Information Support	Information Support Liaise / refer	Information	Information
2nd	Continuity	Support	Staff education		Support	Support Filtering Advocacy Staff education
3rd	Liaise/refer	Filtering	Liaise/refer		Liaise/refer	

Role overlap

The question of role overlap is central to the success of the SBN role. In most interviews, perceived role overlap was seen as a positive aspect of the SBN role. This was because the overlap was held to be in the best interests of women. Overlap occurred mainly in relation to information giving: SBNs were seen to give the same information as a range of other health professionals, including surgeons, oncologists, physiotherapists and social workers, or were seen to repeat to women the treatment plan decisions made by the treatment team. As is evident in the quote below, this doubling or reinforcing of information was described as positive, as it is recognised that patients often retain only a small amount of the information from medical consultations, particularly at diagnosis.

> **Medical oncologist**: Patients and families often need things repeated on a number of occasions … I think what is important is that the [SBN] could … reinforce … what people are being told … Information has to be given and sometimes information is given differently by different people, people feel less threatened by information given by one person versus another, so I think it ought to be an additive, if not a synergistic role, rather than a competitive role … [the SBN] needs to have discussed that with the multi-modal team who's going to make … the ultimate treatment recommendation, to be sure that [the SBN] is conveying the same message.

In other cases, information on the same issues given by SBNs was not seen to be a negative overlap because the information given by SBNs was more general, whereas that given by other specialist treatment team members was more specific to that woman's situation. This happened, for example, in relation to arm exercises prescribed by physiotherapists, who reported that women came to physiotherapy with a useful general understanding of arm exercises, which they then made more specific.

Other positive role overlap occurred in relation to discharge planning (as reported by discharge nurses) and in relation to dealing with families and friends (as reported by a nurse unit manager). The overlap in regard to these more practical organisational issues was again seen as helpful to, rather than hindering good patient care.

There was also some complementary overlap in the area of emotional or psychological care, although allied health professionals made clear distinctions between the interventions they provided and the support role of the SBN:

> **Psychologist:** I guess the way it complements is that we have confidence in each other's skills and resources. I am confident that [the SBN] is able to recognise where emotional support is not enough and patients actually need … psychological intervention … We know each other's roles and we know what is appropriate and what is expected and what is intrusive, and we deal very openly and honestly with each other on those levels.

BCSS volunteers also made a distinction between the support they offer to women and that offered by SBNs. As one volunteer remarked, "The role that the volunteer provides is somebody who's had treatment for breast cancer … It's a very particular kind of role."

Some aspects of role overlap were seen as less positive, and conflict around role boundaries was reported in a few instances. In most instances, however, negotiations between SBNs and treatment team members led to a successful resolution of these issues. In these cases, the problem seemed to relate to role development and the uncertainty caused by the new role. In centres where a nurse had been working in a similar position before the project, there were fewer, if any, instances of such conflict.

> **Clinical nurse specialist (CNS)(Oncology):** I think it was a bit hard at first to work out exactly where she was going and where we were going with our roles and then once we sorted that out it sort of worked a lot better …
>
> **Interviewer:** And how did you deal with the overlap … ? What did you actually do? …
>
> **CNS (Oncology):** We'd sit down and discuss it …
>
> **Interviewer**: … What caused the actual problem? …
>
> **CNS (Oncology):** Oh, I think neither of us was prepared. We probably should have sat down and discussed it more before the [SBN] actually started.
>
> **Interviewer**: How did you and the [SBN] deal with the overlap?
>
> **Social Worker**: By setting clear contracts with each other about what each of us were doing, what tasks we were undertaking and what follow-up we would each provide. So just clear communication and coordination of the intervention plan.

In rare cases where role conflict was reported as having been neither resolved nor improved, infrequent contact and lack of previous experience with SBNs appeared to be significant factors. In one isolated case, communication problems between the SBN and a surgeon led to confusion regarding role boundaries:

> **Surgeon**: She's been given roles that are actually the doctor's role largely, or were done, previously done and are still being done, by the doctor and there was therefore a duplication. Now from my own point of view, I didn't feel it was important that my role be replaced. Or that someone else come and do my job.

Conclusion

Role overlap, in general, was seen as a positive aspect of the SBN role, as long as such overlap did not create confusion regarding role boundaries and core tasks. The development of the role to suit different treatment centres and teams, and the development in each team member of a full understanding of the SBN role, are clearly essential to the successful functioning of the SBN.

Perceived benefits of the model

Benefits to women

> **Discharge nurse**: She was well received by patients. And they felt happier and safer and little bit more secure too.

Treatment team members and SBNs viewed the SBN role as providing important benefits to women. The perceived benefits provided by SBNs can be summarised as follows:

- continuity of care;
- psychosocial support;
- information; and
- increased opportunities for discussion of concerns and issues.

View 1: Continuity of care is enhanced by SBNs, since they coordinate women's progress through the treatment process. Within the focus group discussion, SBNs described their role as a "trouble shooter". SBNs felt well placed to deal with any failures in the coordination of appointments or treatments, and to ensure that no one became "lost" within the system:

> **SBN**: My main job role … was to coordinate the lady's care, so to meet her as early as possible … in her progress through the system and to make sure her care was coordinated if possible. So liaising with all the different areas that she would come in contact with, making sure she had someone that she could refer back to, making sure that she had as much information as she needed and was relevant to her. That she was able to access different resources and literature as well, like through the [State] Cancer Council and the BCSS.

View 2: The SBN's focus on providing support and information means that the psychosocial needs of women are given serious attention. This emphasis also means that women are treated as individuals, and in a more holistic manner, with attention paid to sexuality, spirituality and relationships:

> **Interviewer**: Did you perceive the breast nurse as being an integral member of the treatment team?
>
> **Clinical nurse consultant (Women's health):** Mhmm … I guess because of the support, the fact that the patient has got someone to turn to, and they can put a face with a name, and someone they can relate to, quietly and privately. It just seems to make such a huge difference to their psychosocial wellbeing.
>
> **Interviewer**: Did you feel that the clinical pathway assisted you in detecting women at risk of psychological morbidity?
>
> **SBN**: It certainly helps to really bring out different types of issues that could be adding stress to an individual coming through treatment. I think it's very positive that it helps to give a defined structure, and it certainly gives a much more holistic picture and a much greater assessment of women's needs than purely looking just at … physical information or treatment management with that information. It recognises the effects of breast cancer are much greater than just on the breast.

View 4: As non-medical health specialists, SBNs help women to discuss concerns and issues they may not feel comfortable discussing with surgeons or oncologists. They also have time for detailed discussions with patients that other health professionals may not have. The skills that SBNs have in the area of counselling and support were also seen as important here:

> **Surgeon**: Well, I think the [SBN] possesses better skills about some aspects of patient counselling, not to say the doctors don't have them, but I mean I think probably the [SBNs] are more attuned to some of the aspects that the patients are concerned about. And I think also not being a specialist figure, the patients will often tell [SBNs] about problems they don't think the doctors need to hear about, and they're usually social issues, or marital problems and things that might impact on their treatment.

Conclusion

When asked "Do you feel that the breast nurse is important for ensuring high quality care for women?" 75% of medical specialists and 100% of all other groups interviewed answered positively. This result indicates a highly positive view of the benefits that SBNs provide for women.

Benefits to the treatment team

Participants also stressed the benefits of the SBN model to treatment team members and to the functioning of the team in general. These benefits can be summarised as follows:

- women were better prepared for treatment procedures;
- consultation times of other treatment team members were decreased;
- referrals to other treatment team members increased; and
- SBNs provided education and support to treatment team members.

View 1: Treatment team members felt that women were better prepared for treatment procedures after having discussed these with the SBN. This made the task of organising, discussing and undertaking treatment procedures easier:

> **Clinical nurse consultant (Oncology):** I find [the SBNs] extremely helpful, in the sense that the patients come to the ward with very good pre-operative knowledge. They're well informed of what's going to occur, what to expect pre-operatively, post-operatively. They are aware of the fact that they have drains, etcetera. So it's a huge help to the ward staff.

View 2: Consultation times required by some other treatment team members are reduced. This was seen to be due to the SBNs' information and support-giving roles. General information and support previously given by other health professionals were now given by the SBN, and thus only required reinforcement by others:

> **Discharge coordinator**: I think our nurses would have a shorter time with the patients out in the community because of the role [the SBN] has. She takes over a lot of the counselling and quite often we're providing backup to the counselling she's already done, rather than being snowed down in among it all.
>
> **Interviewer**: Did you find that the presence of [a SBN] influenced your own workload?
>
> **Medical oncologist**: Yes, it probably eased my workload a little bit because a lot of the explanation and a lot of the work that I had to do was a bit quicker and a bit easier.

In other cases, consultation time was not thought to have been reduced by the woman's having seen the SBN, but it was believed that the consultation time of other health professionals was better spent (this perception is reinforced by the economic analysis in Chapter 9).

View 3: Some treatment team members reported receiving more referrals from the SBN (this includes psychologists, physiotherapists and BCSS volunteers):

> **Physiotherapist**: I'm actually attending Clinic now … and that was on the invitation of the breast nurse. And also … if someone comes to Clinic who's got a problem with movement or swelling, then she'll tend to ring me, far more than … she used to.

View 4: SBNs provide education to other treatment team members regarding breast cancer. They become an informational resource for other staff members:

> **Discharge nurse**: She educated all of the staff here. I'd say she was a resource person. If we … needed to know something well, we could just ring her up, get some help.

SBNs also provide emotional and practical support to some treatment team members, especially nursing colleagues:

> **Nursing unit manager**: She's been able to … give the staff lots of advice and confidence in dealing with the patients, both from an emotional and physical point of view.

Conclusion

SBNs are viewed as a positive resource within the treatment team. They ensure that care flows smoothly: namely, that referrals happen when needed, that other health professionals have adequate information aboutpatients and breast cancer issues, and that women are prepared for each treatment stage. They also provide support to their colleagues.

Concerns and problems raised

Concerns and problems regarding women

One important issue raised, particularly by SBNs, concerned duration of care. As described in Chapter 4, the SBN model of care scheduled the final follow-up consultation at 6-10 weeks after diagnosis. In both the telephone and focus group interviews, SBNs stated that they thought this ended their intervention too early. They argued that women are often only beginning adjuvant therapy at this time and might continue to need contact with a SBN during this period, and up to 12-18 months after diagnosis. Other nurses also shared this view, although medical professionals tended to value the importance of women meeting with SBNs less and less as the time from diagnosis increased. These differences of opinion are tabled in Table 5.2.

Other issues raised by SBNs concerned the impact of their interventions on women. Although their interventions were in general viewed as highly positive, there was some concern that women could be disempowered by being "over-helped". Although this was not perceived to have happened, it was raised as a possibility that needed to be avoided. Similarly, SBNs pointed out that the model should not be too strictly applied to every woman. SBNs believed strongly that the strength of their role lay in the attention brought to the individuality of each patient, and that this should not be undermined by a strict adherence to a predetermined schedule of questions and issues. The individuality of each treatment centre was also emphasised – the model was seen to work best when it was adapted to local conditions.

> **SBN**: There are certain things that are very important to me … control needs to always be with the patient, and for them to feel that they have control. Because I could cosset them, wrap them in cotton wool and take them through their treatments and make sure they have the nicest of times, sort of, but I think that's not really what's going to help that woman who has to deal with her life.
>
> **SBN**: I often talk about not being prescriptive, that you're actually still able to see every woman as an individual, not become so stuck in a role or a model that you fail to see what this person needs may be totally different to another person.

Another issue raised by SBNs was the availability of services to which to refer women. Especially in relation to psychological services, clear gaps were in evidence, where hospitals simply did not employ psychologists. Women in need in these circumstances were referred to psychiatrists or general practitioners, but in some cases it was felt that this may not have been the best option.

Table 5.2: Perceptions of the importance of women seeing a SBN at designated times: percentage of participants who thought it was very important (answered 7, 8, 9 or 10 on a scale of 1 to 10), by professional group

	Time of consultation with SBN						
Professional group	**Diagnosis** %	**Pre-Operative** %	**Post-Operative** %	**2-3 months** %	**3-6 months** %	**6-12 months** %	**18 months** %
Specialist medical professional n=22	82	63	82	63	36	23	14
SBNs n=7	100	100	86	100	100	86	57
Nurses other than SBNs n=13	100	92	100	100	77	62	54
Community health professionals n=3	67	100	67	67	100	100	33
Allied health n=11	91	91	100	91	73	55	27
BCSS volunteers n=3	67	100	100	100	100	67	67

Problems and concerns regarding the treatment team

Although significant problems were not reported as having occurred with any SBNs, numerous participants raised the issue of possible problems. These included concerns that responsibilities for some aspects of medical care may be inappropriately handed over to SBNs. Also there were some concerns – which again were not reported as having happened – that SBNs could desire too much autonomy, or could give medical or other information that differed from that decided upon by the treatment team. These eventualities were not seen as likely, but were reported as possible "if you got the wrong person in the job".

> **Radiation oncologist**: I think if some of the medical responsibility is off-loaded onto the [SBN], there is the potential for that to be disadvantageous. But I think, in practice, I haven't seen any disadvantages.
>
> **Radiation oncologist**: There are situations where the nurse perhaps taking on too much of an advocate role can perhaps challenge a surgeon in what they are recommending … but it's not happened in our situation.
>
> **SBN**: I'd hate to see it that a doctor felt that because he had a nurse he could spend less time with patients.

These quotes indicate unsubstantiated concerns. However, their existence could impact on the functioning of SBNs in any particular context. As for the discussion of role overlap, it seems that the issue here is one of education and familiarity. Because there are so few SBNs in Australia, there is a tendency to view the qualities of the role as pertaining to individual nurses, rather than to the role itself. Such views will presumably decrease as more nurses take up similar roles.

Skills and qualifications

Interviewees were asked three quantitative questions concerning the skills, qualifications and nursing level they considered appropriate for SBNs. These issues were also explored qualitatively.

When asked what clinical skills a SBN should possess, the three most common responses were knowledge and experience in the areas of surgical wards, chemotherapy and radiotherapy. As is evident in Table 5.3, medical professionals tended to emphasise counselling and communication skills, while nursing professionals, SBNs and allied health professionals tended to place a stronger emphasis on knowledge and experience in surgical wards, chemotherapy and radiotherapy. Clinical skills in palliative care were only rarely mentioned, as were lecturing skills.

Table 5.3: Perceptions of the clinical skills that SBNs should possess percentage of responses endorsing the SBN's need for skills & experience, by professional group

	Professional group					
Clinical skills	**Specialist medical professional (n=22) %**	**SBNs (n=7) %**	**Nurses other than SBNs (n=13) %**	**Allied health (n=11) %**	**Community health professionals (n=3) %**	**BCSS volunteers (n=3) %**
Communication skills	56	43	38	36	66	66
Counselling skills	77	29	23	45	33	100
Surgical ward	95	100	100	91	100	100
Adjuvant treatment*	41	71	81	73	66	66
Palliative care	9	0	8	0	33	33
Education skills	0	0	8	9	0	0
Other	23	43	39	27	33	33

** Includes endorsement of radiotherapy and/or chemotherapy knowledge/experience*

There was less agreement among interviewees concerning the qualifications that a SBN should possess. Although it was generally agreed that SBNs should have qualifications in oncology and/or breast cancer, the issue of tertiary courses versus non-tertiary courses divided participants. Counselling qualifications were also seen as desirable by some participants.

The position classification for a SBN is important in relation to determining both the level of expertise and the financial remuneration for the position. This issue of position classification produced some disagreement across our participant group (Table 5.4). Five out of seven SBNs stated that the SBN role required a Clinical Nurse Consultant (CNC) nursing level. The majority of other nurses also stated that a Clinical Nurse Specialist (CNS) or CNC level was required. Many non-nursing interviewees, on the other hand, professed ignorance of nursing levels and job classifications, with seven respondents unable, or unwilling, to answer the question. Some interviewees expressed disapproval of any focus on such categories, arguing that they are unnecessary and do not reflect desirable nursing skills.

Interviewer: What nursing level do you think is appropriate for a SBN? Just a registered nurse? Or should she be a clinical nurse specialist? Or a clinical nurse consultant?

Medical oncologist: Oh again, jargon! What's important to me is a person who's actually had hands-on experience, who knows. Now you can categorise them at whatever is the politically appropriate term for a particular nurse – what I'm saying is I need people with experience. I don't need an administrator who's read a book on breast cancer and then because she has a PhD in 'nose-ology'… to come and tell me about breast cancer!

Surgeon: Well, this will upset the hierarchy but, quite frankly, I think most of these things are an absurdity. I think that what she needs to be is a good nurse, a good communicator and where people want to put them into that … made-up hierarchy, I really don't know!

Table 5.4: Perceptions of nursing level appropriate for a SBN, by professional group

	Professional group					
Nursing level	**Specialist medical professional (n=22)**	**SBNs (n=7)**	**Nurses other than SBNs (n=13)**	**Allied health (n=11)**	**Community health professionals (n=3)**	**BCSS volunteers (n=3)**
RN	2	0	3	1	4	2
CNS	5	2	5	0	3	1
CNC	3	5	5	2	1	0
Unsure	8	0	0	0	0	0
No response	4	0	0	0	3	0

It is interesting to compare these answers with the qualitative data obtained regarding the skills exercised by SBNs in their role. In contrast to the answers above, there was strong agreement that SBNs needed a high level of knowledge about breast cancer and its treatments, as well as good counselling and communication skills. SBNs were expected to be able to establish good rapport with patients, to liaise effectively with treatment team members, and to educate others. They were also expected to update their knowledge and skills regularly, through professional development. The levels of knowledge required were very high:

> **SBN**: She needs to know a lot about the types of surgery, … what to expect after, what the implications of the prognostic [results are] … what the words mean, because the patients ask a lot about that. I think she needs to have a good clinical or a good physiological view of what it's all about.
>
> **Medical oncologist**: That person needs to know all aspects of breast cancer management from the time effectively of mammographic screening, fine needle biopsy, really needs to be able to take a person … who appears with a lump right through to the end.

Communication skills of a high order were also seen to be necessary: SBNs need to able to communicate complicated information to women and their families and to communicate with all members of the treatment team. Listening skills were also often mentioned. Other skills reported as necessary to, or evidenced by, SBNs included wound assessment, psychosocial and sexual needs assessment, self-reliance, working well under pressure, ability to refrain from getting personally or emotionally involved, good knowledge of hospital systems, ability to work well in a team, advocacy skills, and knowledge regarding the impact of a breast cancer diagnosis on a woman's life.

When compared with the relevant State Nursing Federations' descriptions of each nursing level, these skills are commensurate with those required for a CNS (WA) or CNC (other States) position. Thus, the SBNs in this study were seen as working as advanced, expert nurses.

There is an important issue here concerning awareness of nurse education and qualifications. As stated earlier, there was a tendency among our participants to believe that the skills held by "their" SBN had more to do with personality than with training or professional achievements. Although these personal factors (a sense of humour, an outgoing personality, empathy, women-centredness, a caring personality, maturity, being a woman) may play a part in the enactment of the SBN role in certain contexts, these cannot be considered central to the role as a professional position. A dominant focus on personality factors is problematic for the acceptability and viability of SBN positions in Australia. Unless SBNs' professional skills are recognised and valued as learnt skills, their work will be undervalued, and their positions undermined.

Conclusion

The SBN role was highly valued by representatives of every member of the treatment team. Levels of acceptability were high in this study, with the majority of participants indicating both a good basic understanding of the role, and a very positive view of it. Most treatment team members saw the role as facilitating the provision of high quality care to women, and as improving the functioning of the multidisciplinary treatment team.

Chapter 6: Women's perceptions of the specialist breast nurse role

Introduction

This chapter reports the responses of women in the intervention group. Their experience of the SBN model provides a valuable source of feedback on its acceptability. Women rated their satisfaction in relation to:

- what the SBN did (including the amount of emotional, practical and religious support, information, resources and referrals offered);
- when the support was offered (including the timing and frequency of consultations, the SBN's availability and accessibility, continuity of care provided by the SBN, and the SBN's ability to coordinate care within the multi-disciplinary team); and
- the importance of the care provided by the SBN as a part of their overall care.

Method

Women evaluated the model at two months post-diagnosis and again at six months post-diagnosis by completing a self-administered questionnaire. The two month questionnaire assessed women's perceptions of their initial consultations with the SBN during the time of diagnosis, decision-making about treatment and surgery. The six month questionnaire explored women's perceptions of care received from the SBN during the period of adjuvant therapy, and appraised the overall care provided by SBNs.

Women were also given the opportunity of providing additional comments at the end of both questionnaires in regard to their own personal situation and/or providing suggestions as to how the SBN role can best meet the needs of women with breast cancer.

A reply-paid envelope addressed to the National Breast Cancer Centre was enclosed with the questionnaires so that both the SBN and treatment team members remained blind to the women's responses.

Data analysis

Quantitative data was analysed using the statistical package SPSS Version8 for Windows, and frequencies and descriptive statistics were carried out.[1] General comments were coded and sorted for recurring categories. No limitations were placed on the number of categories coded per questionnaire. Quotes used are from different women and were chosen as articulating a common response. The results from the two questionnaires have been amalgamated and will be discussed together here.

Results

Response rate

Of the 240 women consenting to participate in the project, 219 (91%) completed the two month questionnaire and 209 (87%) completed the six month questionnaire. The response rates by Centre are presented in Appendix 26.

Characteristics of women completing the questionnaires-including age, language spoken at home, education level and prescribed treatment regime-were compared with those of women who did not complete the questionnaires. Women who did not complete the two month questionnaire were on average two years younger (t=0.65, 237df, p=0.51), more likely to be married or in a relationship (χ^2=2.1, 1df, p=0.15) and tended to be more educated (χ^2=2.6, 1df, p=0.27). These differences were not statistically significant. There were no differences between the groups in regard to language spoken at home ((χ^2=0.67, 1df, p=0.41), or having received chemotherapy (χ^2=2.3, 1df, p=0.13) or radiotherapy (χ^2=0.35, 1df, p=0.55). Likewise, comparison of responders with non-responders for the six month questionnaire revealed the groups to be similar to those reported above for the two month questionnaire, with no significant differences found.

Overall, 176 women (80%) provided additional comments about the SBN and/or further details about their own experiences with breast cancer in the two month questionnaire, and 144 women (68%) responded similarly in the six month questionnaire.

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[1] The sample sizes were too small to provide meaningful comparisons across centres.

The SBN as a link between women and the treatment team

One aspect of the SBN's role is to ensure effective communication, both among members of the treatment team and between the treatment team and women consumers.

Women were asked whether they had needed help with being introduced to treatment team members, understanding each member's role, and ensuring that the medical staff were informed of issues related to their care. Over 80% of women reported that they had needed help with these aspects of care (Appendix 27). SBNs were viewed as good communicators, skilled in explaining issues to women (98%) and in conveying women's needs to her doctors (96%) and, to a lesser degree, to community health workers (86%). Continuity of care was rated as a major benefit by 88% of women, and 97% of women reported that they benefited from ongoing contact with the SBN (Appendix 27).

Women commented on the link provided by the SBN:

> I felt the breast nurse was a valuable addition to the team. She provided the contact between doctor and patient and nurse and patient. Without the breast nurse, I would have felt uninformed and alone. Her personal input made me feel safe and important – not just a statistic or file number.
>
> I found the role of the breast care nurse very important as the link between me and "the system", between me and the surgeon. She was the human link, providing personal attention and care that doctors are often not able to give. She was the one constant throughout the whole process.

The SBN's ongoing contact with women and members of the treatment team provides opportunities to link women with relevant health professionals and support groups at different treatment phases. Women were asked if the SBN had suggested talking, or offered the chance to talk, to members of the multi-disciplinary team and support organisations. As shown in Appendix 28, women were most commonly referred to the BCSS (84%) and Cancer Information Service (CIS) (76%). Roughly a quarter of the women indicated that professional counselling services did not apply to them, and of the remaining women, 67% were offered referral to a social or welfare worker and 52% were offered referral to a professional counsellor. Likewise (excluding women who indicated they did not need a referral to other members of the treatment team) about 60% of women were offered the opportunity by the SBN to see a physiotherapist, radiotherapy or chemotherapy nurse and either a GP or community nurse.

Providing information about treatment issues and support networks

Women rated the amount of specific and clinically relevant information they received from SBNs. Topics included:

- diagnosis;
- prognosis;
- treatment choices;
- clinical trials;
- breast reconstruction;
- prostheses;
- discharge from hospital; and
- support services such as the BCSS, CIS and support groups.

SBNs were most often rated as having provided the right amount of information when discussing diagnosis (92.5%) and prognosis (91%) (Appendix 29). Many women commented that the SBN had more time for questions than doctors, and importantly, was able to translate medical jargon into plain terms. The SBNs' role in providing clinical information was a common, recurring theme in the free response section. One benefit of seeing SBNs on multiple occasions was that women were not overloaded with information.

> [The SBN] was able to prioritise and sift information given to me so that my poor brain and emotions weren't *too* overloaded at any one time. Her timing with what I *needed* to know and *when* I needed to know it was excellent. [consumer's emphasis]

Women reported they would have liked more information about radiotherapy (12%), results of surgery (10%), breast reconstruction (10%), discharge and treatment planning (10%) and practical support (10%).

Providing resources

Women were asked whether the SBN had offered resources about breast cancer in general, their own diagnosis, and information for their partners and children. As shown in Appendix 30, all women were offered printed resources about breast cancer and 82% were offered a breast cancer fact sheet. In regard to their own diagnosis and treatment, 45% of women were offered written information, and 73% had at least some of their consultations with the SBN taped. Sixty percent of women agreed that these tapes had been helpful.

In relation to resources addressing specific needs, 74% of women in relationships were offered resources for their partners and 58% of women with children were offered resources for their children.

These findings support results reported in Chapter 7, which indicate that SBNs were important in accessing information.

Emotional support offered

Women reported their level of satisfaction with the amount of emotional support offered by the SBN during the different treatment phases. Appendix 31 shows that almost all women (98%) were satisfied with the support offered by the SBN, both pre-operatively and post-operatively. However, 6% reported that they were not satisfied and 6% were very dissatisfied with the emotional support provided by the SBN at later stages of treatment. Overall, 10% indicated that they would have liked a little more support from the SBN and a small percentage (2.5%) expressed a desire for a lot more support from the SBN.

For the majority of women (86%) SBNs offered the right amount of emotional support. Eighteen percent felt that they also required counselling from a psychosocial professional. Of these women, 65% reported that the SBN had offered referral for professional counselling (see Chapter 8 for further discussion).

Although it appears that women could distinguish between the level of emotional support that SBNs could offer and professional counselling, Appendix 32 reveals that the counselling skills of the SBN were nevertheless appreciated. Ninety-eight percent of women reported the SBN to be a good listener and 94% felt that the SBN knew when, and when not, to talk. These findings complement the results reported in Chapter 7, that women in the intervention group were significantly more likely to use SBNs for support than women in either of the control groups. Emotional support was also the most frequently addressed category in the free response data:

> My [SBN] gave me the confidence to deal with breast cancer in a positive way. She didn't give me any false assurances but "painted" a realistic and hopeful picture for the future.
>
> My experience with my [SBN] was very supportive. I had lost my partner of 34 years and my business was going downhill. The last thing I needed was a diagnosis of cancer. [The SBN] was my base. She was with me after diagnosis and during consultations with the surgeon. [The SBN] later explained what was said. She asked questions on my behalf that I would never have thought of asking. I knew I could always contact her by phone … Because of her, I came through my bilateral [mastectomies] in a positive frame of mind.
>
> [W]ithout her, I'm not sure I would have made it this far. She was someone to lean on who was not emotionally involved to the point that I had to protect [her] from my feelings. Books could never replace that kind of support. Information is one thing, but a hand to hold is far better. She was with me all the way through. I feel all women deserve this support.

Other communication skills were perceived as less developed. For instance, 25% percent of women reported that they were unable to share their feelings with the SBN and 15% of women felt their needs were not communicated to their general practitioner or other health workers (Appendix 32).

However, women who had had previous experience with breast cancer (either personally or through a close friend or family member) commented on the difference in emotional support available to them and their families, compared with their previous experience.

> Having had breast cancer five and a half years ago, I was so happy to find so much had changed for the better. I felt that my needs were met, especially by the [SBN].

Women also commented on the support skills of the SBN. SBNs were most frequently referred to as kind and/or helpful, while others described SBNs as "warm", "caring", "approachable", "compassionate", "knowledgeable", "considerate" and/or "dedicated". Several women noted it was important for the SBN to be a woman.

Support for family and friends

Women were asked whether the SBN had provided their family and friends with an opportunity to discuss their feelings and seek information about the illness. Eighty-two percent of women reported that family and/or friends required information about the illness, with 76% needing the opportunity to discuss their feelings and ask questions. Over 94% were satisfied with the emotional support provided to their family and friends by the SBN (Appendix 33). These data support the results reported in Chapter 7, that these women's families were more likely to use SBNs for support than the families of women in the control groups.

Information about practical support

Women were asked if the SBN had provided information about practical matters such as understanding the cost of treatment, choosing a hospital, organising travel, and obtaining a prosthesis. Less than 50% of women reported requiring assistance of this nature (Appendix 34). Practical issues to do with understanding the length of admission to hospital and what to expect on discharge were applicable to 85% of women. Although the majority reported being satisfied with the amount of practical information supplied by the SBN, 11% would have liked more information about what to expect post-discharge. Of the 55 women indicating that they required assistance with chores while recovering at home, 24% would have liked more help from the SBN in organising this assistance.

Meeting cultural/spiritual needs

Women were asked whether SBNs had offered information, resources or support of a cultural, religious or spiritual nature. Sixty-four percent of women reported that they were offered resources specific to their culture, and 59% of women confirmed that they were given the opportunity to talk with another woman from their own culture or language group (Appendix 35). Fewer women reported being offered support for their spiritual needs, with only 37% given the opportunity to discuss the spiritual aspects of having breast cancer and 33% the chance to speak with another woman with similar beliefs.

Women's perceptions of the SBN model

Timing of consultations

The timing of the nurse-initiated consultations was designed to coincide with the key treatment phases. Women were asked to evaluate how appropriate it was to see the SBN at these designated times. Appendix 36 shows that 99% of women were satisfied with the timing of the initial consultations during their early phases of treatment. In 81% of cases, SBNs helped to make treatment options clearer and 92% of women reported that their SBNs had assisted them in the decision-making process. Likewise, 99% of women reported that seeing the SBN pre-operatively and post-operatively was helpful. However, 11% of women would have preferred some changes to the timing of consultations during adjuvant therapy, and 13.5% would have preferred more than two follow-up sessions. Of the women who commented on the timing of consultations in the free response section, there was strong support for the SBN intervention to continue for at least the duration of adjuvant therapy (see Chapters 4 and 5 for further discussion on consultation timing).

> With hindsight, the most dangerous time for me was the month following the end of radiotherapy. I thought the worst was behind me and that I would resume my normal life, but I could not. I was left to my own devices. That is when the [SBN] should have checked on me regularly – as it happened, I fell into a deep depression.

Structured contact with SBNs

Although most women endorsed the set schedule of contact with SBNs, 17% reported that they would have preferred to see the SBN on request only (Appendix 37). However, one advantage of scheduling ongoing consultations with SBNs is that women do not need to actively request support or initiate contact with the SBN.

> I found my [SBN] very good. I am… a bit shy and find it hard to make a phone call. I would hesitate a little. I am sure there would be others like it as well.

More than 90% of women indicated they were satisfied with the availability and accessibility of the SBN, and many women commented on the SBN's ongoing availability.

> While I was satisfied with the number of times I saw the [SBN], it was good to know that she was available to talk to anytime I needed to. I found her daily visits at the hospital very comforting. It made me feel like I had some control over what was happening.

Overall appraisal of the SBN intervention

Women appraised the overall impact of the SBN on their satisfaction with their treatment. Eighty-seven percent of women believed that their SBN had significantly contributed towards their care. Of the women indicating that the SBN had made a difference to their care, 55% felt that the contribution was major. The frequency of free responses that conveyed women's gratitude to their SBN illustrates the importance that women attached to the care provided by SBNs. However, there were a few instances when SBNs were unable to adhere to the model due to workload demands or being on leave (see Chapter 3 for further discussion). In these cases, face-to-face contact with the SBN was limited, with the majority of consultations taking place by telephone. Feedback from these women indicated that continuity of care was affected and the SBN had not had a major impact on their overall care.

Finally, women were asked to nominate the degree of importance (if any) in selecting a hospital with a SBN. Only 1% of women indicated it did not matter while 50.5% of women indicated they would recommend to a friend that a hospital with a SBN was preferable, a further 48% of women would advise only choosing a hospital with a breast nurse.

As shown in the following quote, women's preference for a breast nurse is being voiced and acted upon:

> I have spoken to my own doctor and urged him to get the practice to refer women to [Hospital X] because of the breast clinic and the value of the [SBN] who will walk women through what can only be described as a mine-field.

Suggestions for refining the SBN model

Some constructive comments were made about the way the SBN role could better meet the needs of women.

- The main suggestion was to extend the length of contact with the SBN, namely for the duration of adjuvant therapy. For many women, the need for information and support was as important in the later stages of treatment as it had been at diagnosis. This recommendation supports the finding that women were more satisfied with the amount of information and support provided during the earlier phases of treatment than at other times.

> [SBNs'] roles are focused on the period of diagnosis and surgery. Extending contact throughout chemotherapy and radiotherapy to enable continuity of care would dramatically reduce isolation and segmentation of care.

- A few women experienced disruptions in the continuity of SBN care due to circumstances such as annual leave or simply because they required the services of the SBN over a weekend. It was suggested that a backup SBN be available at these times.
- Another emerging theme was the need for SBNs to tailor the amount of emotional support and information given to women's needs. A couple of women made it quite clear they did not require any support from SBNs.
- The range of topics that SBNs covered was mentioned by a few women. Some women who went on to experience complications felt that they could have been better prepared. A few women mentioned specific topics they would have liked more detail on, for example certain medical procedures, alternative therapies etc.
- Finally, there was consensus among rural women that the SBN was a valuable asset to women in remote areas. A sense of isolation can be even stronger when distance separates a woman from her family during treatment. During this time, the SBN had provided much needed support. It was especially distressing for these women that the SBN service would no longer be available at the end of this project for other women in similar circumstances.[2]

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[2] The rural site was unable to sustain the SBN position on completion of the project.

Discussion

Women's evaluation of the SBN intervention was extremely positive. SBNs were perceived to be well-suited to the role of coordinator and effective in communicating women's needs to other members of the treatment team. SBNs were perceived to be one constant throughout the treatment process. Two-thirds of women in need of professional counselling reported that they were offered referral to a psychosocial professional. Feedback from women confirmed that SBNs were effective in providing information, emotional and practical support both to the women themselves and to their families.

SBNs were most often regarded as having provided the right amount of information at diagnosis, when treatment choices and prognostic issues were discussed and preparations for surgery made. These findings support evidence that many women prefer detailed information about treatment goals and options. However, ongoing access to information, particularly in the phases of adjuvant therapy, needs to be maintained.

SBNs were an important source of emotional support for women and their families. However, a small proportion of women were dissatisfied 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 request, it appears that women had difficulties accessing SBN support at this time.

Surprisingly few women 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. Studies exploring spirituality and nursing practice suggest that nurses often report feeling ill-equipped to deal with their patients' spirituality (Piles, 1990, cited in Nolan and Crawford, 1997; Gray 1994, cited in Catterall, 1998).

The difficulty of integrating spiritual care into the nursing process has been attributed to a lack of a clear, operationalised definition of spirituality (Goddard, 1995; Harrison, 1997; Martsolf and Mickley, 1998) and the absence of guidelines for assessing spiritual distress and providing spiritual care (Ross, 1994). Although illness often precipitates a crisis of reappraisal of who and what we are (Goddard, 1995), it is terminally ill patients who are more likely to have a greater spiritual perspective (Reed, 1987, cited in Cawlay, 1997). This association between spirituality and terminal illness may actually discourage SBNs raising spiritual issues for fear of inadvertently conveying a negative message about a woman's prognosis. However, there is evidence that spirituality can influence health and wellbeing (Ross, 1995) and may enhance patients' coping skills (Goddard, 1995). It is therefore important that SBNs acknowledge the women's cultural and spiritual beliefs and the impact that these may have on their expectation of nursing care. SBN training should include communication skills for discussing spiritual issues when appropriate, and awareness of pastoral care services.

The structure of the SBN intervention received a favourable response from the majority of women. While the earlier consultations were well-timed, slight changes to the follow-up consultations were recommended, including perhaps an additional session and an extension to the service. Likewise, while the majority benefited from the set schedule of contacts with the SBN, the intervention needs to be flexible enough to cater for women who prefer less structure.

Conclusion

Women found the SBN intervention to be an important component of their overall treatment. Women indicated that this care should be available to every woman treated for breast cancer.

Chapter 7: The impact of the specialist breast nurse model on women's perceptions of care

The Specialist breast nurse (SBN) demonstration project was conducted to assess the feasibility of implementing the SBN model of care in diverse Australian settings. The project also included an evaluation from the consumer's perspective. This chapter reports on the impact of the SBN model on women's perceptions of the care they received in their treatment for breast cancer, are reported and compared with the perceptions of two groups of women treated for breast cancer without SBN intervention. The three groups are described in detail below.

Method

Study design

The effect of SBNs has been demonstrated in multiple, randomised controlled trials. The primary purpose of this project is to identify factors associated with the implementation of the evidence-based SBN model of care. Since an evaluation of the SBN's impact is a secondary aim, a randomised control trial was not considered the most appropriate study design. In the consumer evaluation component of the project, the SBN model of care was provided for a sample of women with breast cancer (the intervention group) and compared with two non-randomised groups without SBN contact (the control groups). Neither of the two control groups was free from bias, but both provided valuable comparative data sources.

The first control group was a sample of Australian women diagnosed with early breast cancer. This sample was from a separate study of the perceptions of care of women with early breast cancer. The women were accessed though State cancer registries (Williams *et al.* in review 2000). This sample provides a national benchmark of consumer perceptions, enabling the evaluation of interventions.

The second control group was a sample of women treated at the Collaborating Centres within the 12 months before the SBN protocol was implemented. This retrospective control enabled initial comparisons with the national sample, to determine baseline differences between the Collaborating Centres and the national standard before the introduction of the SBN model. The Collaborative Centres had been initially chosen as centres of excellence, hence the expectation that they would provide above average care. The retrospective sample also provided a "pre" sample within the Collaborating Centres to observe changes that coincided with the introduction of the SBN intervention. However, differences between this sample and the intervention group may not be wholly attributed to SBN intervention, as the study design did not control for other changes occurring during the life of the project.

The three-group design enabled the assessment of women's perceptions of care along a continuum of exposure to SBN care. The national sample documented women's recall of access to any SBN across Australia, and allowed initial comparison of the responses of women who had no systematic access to SBN care with those who did have such access. The retrospective control allowed the perceptions of women in high quality centres with some availability of a SBN to be compared to those of women in the intervention who were receiving the highly structured, evidence-based SBN intervention.

National Consumer Survey

Women in the three groups were interviewed about their perceptions of the treatment they received for breast cancer using the National Consumer Survey, a semi-structured interview schedule previously validated for the study of the national sample (NBCC, in review). The National Consumer Survey was designed to assess women's perceptions of the psychosocial, physical and practical support provided to them. This included the amount of information given about treatment options, clinical trials, information resources offered, support provided and practical assistance. Women's satisfaction with aspects of their care was assessed, such as the way the news of breast cancer was given, involvement in decision-making, support, treatment and continuity of care and information received.

Women completed the survey between 6 and 12 months after their breast cancer diagnosis. The survey was conducted over the telephone by trained interviewers from an external research agency, using the CATI system. All women had previously consented to the survey in writing and nominated their preferred times for the telephone interview.

Recruitment and response rates

Intervention group

The initial recruitment procedures for the intervention group are described in Chapter 2. Women were re-contacted by mail two months before the survey, to obtain their consent and preferred contact number and times for the telephone interview. Of the 240 women who received the SBN intervention, 228 subsequently consented to the survey, five refused and seven did not have phone numbers or were unable to be contacted. The telephone interviewers successfully contacted 167 (70%) women, and these completed the National Consumer Survey (see Appendices 38 and 39 for response rates by Centre).

National sample

To ensure that the National sample was representative of the Australian population of women with early breast cancer, women were sampled through the State cancer registries. All States participated except Tasmania, where an ethics committee declined approval. With the consent of participating clinicians, 838 eligible women were sent a letter about the survey; 615 (73%) consented to take part; and 544 (65%) completed the survey (NBCC, in review). Twelve women had been treated at the Collaborating Centres during the retrospective control period. In comparative analyses their data were grouped with retrospective control, leaving 532 in the National sample.

Retrospective control from Collaborating Centres

Women in the retrospective control group met the same eligibility criteria as the intervention group, but had been treated at a Collaborating Centre less than a year prior to the demonstration project. Centre D nominated only site D2 for the retrospective control.

A data manager at each Collaborating Centre identified women who were newly diagnosed with breast cancer or a recurrence of breast cancer between March and December 1997. Each woman's clinician was identified from her records and contacted by the data manager to verify the woman's eligibility to participate. Nine out of 10 clinicians identified agreed to participate. The treating clinician advised if an otherwise eligible woman was too unwell to be contacted.

Women not excluded by their clinicians were sent a letter from the Collaborating Centre asking them to participate in a consumer survey, and an information sheet and consent form from the National Breast Cancer Centre. If women did not reply, a further letter was sent and/or contact was attempted by telephone.

Of the 229 women treated at the Collaborating Centres during this period, 54 (24%) women were considered ineligible by clinicians (Appendix 40). The remaining 175 (76%) women were contacted by letter. A total of 145 women agreed to participate in the survey (40 from Centre A, 67 from Centre B, 21 from Centre C, and 18 from site D2). Of these, 133 completed the survey, three declined at the time of interview, eight terminated the interview prematurely, and six were unable to be contacted.

Statistical note

The proportion of women from each Collaborating Centre differed in the retrospective control and intervention groups (Appendix 39). As Centre D nominated only site D2 for the retrospective control, compared with the intervention group, there was a four-fold decrease in the proportion of women from that centre who participated in the retrospective control.

In the analysis of the impact of the SBNs, differences between Centres were controlled for by stratification. In the tables showing the comparison between the intervention and retrospective control (Appendices 41-54), percentages in the retrospective control have been adjusted to reflect the distribution by Collaborating Centre in the intervention group, and as such the percentages in the retrospective control differ from their unadjusted figures.

Unless otherwise stated, all chi square analyses have one degree of freedom.

Socio-demographic characteristics

The background characteristics of women who completed the National Consumer Survey from the national sample (n=532), retrospective control (n=133) and intervention group (n=167) are reported in Appendix 41. “Between group” comparisons are reported in Appendix 42. The socio-demographic characteristics are shown for both the full sample of 240 women who took part in the intervention study and the sub-group of 167 who completed the National Consumer Survey.

Unless otherwise stated, the data for each group in Appendix 41 were not statistically different. Statistically significant differences observed between the groups included:

- National sample and retrospective control

  The retrospective control were found to have a significantly lower level of education, and were less likely to be married or in a defacto relationship than the national sample (Appendix 42).

- National sample and intervention group (n=167)
  The intervention group were on average 2.2 years younger than the national sample.

- Retrospective control and the intervention group (n=167)
  Women in the intervention group were on average 2.8 years younger and more highly educated than those in the retrospective control group. However, differences in age and education were no longer significant after stratification by Collaborating Centre.

Results

Experiences of breast nurses by women in the national sample

Results from the national sample indicate that less than half of women treated for early breast cancer nationally could recall having any contact with a breast care nurse, regardless of the breast nurse's training or the basis of her intervention (Table 7.1). Women treated as public patients were more likely to recall seeing a breast nurse as part of their treatment (χ^2 5.72 p=0.02).

Table 7.1: Women with early breast cancer in the national sample seen by any breast nurse

	Characteristic						
	Overall	**Age**		**Residence**		**Place of surgery**	
Number of times seen	n=544	26-49 n=130	50-94 n=414	Urban n=340	Rural n=204	Public n=234	Private n=308
At least once	48 %	45 %	43 %	41 %	49 %	50 %	39 %
Not at all	52 %	55 %	57 %	59 %	51 %	50 %	61 %

To enable comparison with a systematic breast nurse intervention, the national sample data were examined to determine what proportion of women had received at least three contacts with the BN (pre- and post-operatively, and a follow-up, referred to as the "BN3 plus" model). The perceptions of the 58 women (11%) who had received the BN3 plus were compared to perceptions of those who had no BN contact (Table 7.2). In particular, their perceptions concerning the support and information they received were analysed. Women in the BN3 plus category reported significantly more favourable perceptions of care in most areas of support and information than those with no BN contact.

Table 7.2: Differences in perceptions of care according to level of contact with a breast nurse, within the national sample

	Characteristic					
Perception	**No BN (n=244)**		**BN3 plus* (n=58)**		**Notes**	
Support (received enough)	**n**	**%**	**n**	**%**	χ^2	**p=**
▪ Woman herself	185	76	54	93	8.5	0.004
▪ Woman's family	149	61	49	85	11.4	0.001
Information (received enough)						
▪ Surgery	189	78	45	78	0.0	ns
▪ Side effects	162	66	47	81	4.7	0.03
▪ Follow-up	178	73	50	86	4.5	0.04
▪ Clinical trials	24	10	14	24	8.7	0.003

**BN3 plus = saw BN pre- and post-operatively and a follow-up*

Differences between the national sample and the retrospective control

Data from the retrospective control were compared with the national sample to determine whether the Collaborative Centres were different before the introduction of the SBN. Table 7.3 shows the aspects of care for which the national sample and retrospective control differed significantly ($p<0.05$).

Breast nurse contact and support

Overall, significantly more women in the retrospective control reported contact with a BN than women in the national sample (Figure 7.1, $\chi^2 = 126.9$, $p<0.001$). Women in the retrospective control were more likely to use a BN for support for themselves or their families than in the national sample.

Information and treatment

There were a number of areas about which women in the retrospective control received significantly more information than the national sample (Table 7.3). More women in the retrospective control reported being adequately informed about surgery, follow-up care, and likely cost of treatment. More women in the retrospective control also reported being informed about clinical trials than in the national sample, and being offered more information resources-such as a hospital fact sheet, and an audio-tape of a consultation with a member of the treatment team.

Table 7.3: Significant differences in the perceptions of care between women in the national sample (NS) and the retrospective control (RC)

	Group		Note
Characteristic	**NS (n=532)**	**RC (n=133)**	χ^2 (1 df)
Woman used BN for support	124 (23%)	79 (59%)	65.3; $p<0.001$
Family used BN for support	37 (7%)	35 (26%)	41.3; $p<0.001$
Information (received enough)			
▪ *Surgery*	421 (79%)	118 (89%)	6.92; $p<0.01$
▪ *Follow-up care*	408 (78%)	115 (87%)	5.43; $p=0.02$
▪ *Likely cost of treatment*	315 (70%)	64 (83%)	5.72; $p=0.02$
Breast prosthesis			
▪ *Received*	175 (33%)	56 (42%)	3.76; $p=0.05$
▪ *Received & given enough Information*	123 (70%)	50 (89%)	8.12; $p=0.004$
Told about clinical trials	73 (14%)	29 (22%)	5.34; $p=0.02$
Information resources			
▪ *BCSS booklet*	289 (54%)	86 (65%)	4.93; $p=0.03$
▪ *Hospital fact sheet*	181 (34%)	58 (44%)	4.24; $p=0.04$
▪ *Audio-tape of a consultation*	19 (4%)	18 (14%)	20.07; $p<0.001$

Women in the retrospective control were also more likely to receive external breast prostheses and have a shorter hospital stay than women in the national sample.

In summary, women in the retrospective control group reported more favourable perceptions of care across a number of indicators than women in the national sample. This supports the process of selection of the Collaborating Centres as centres of excellence. In evaluating the impact of the SBN model of care, the intervention group was therefore compared with the retrospective control.

Figure 7.1. Contact with breast nurses in the national sample and retrospective control groups

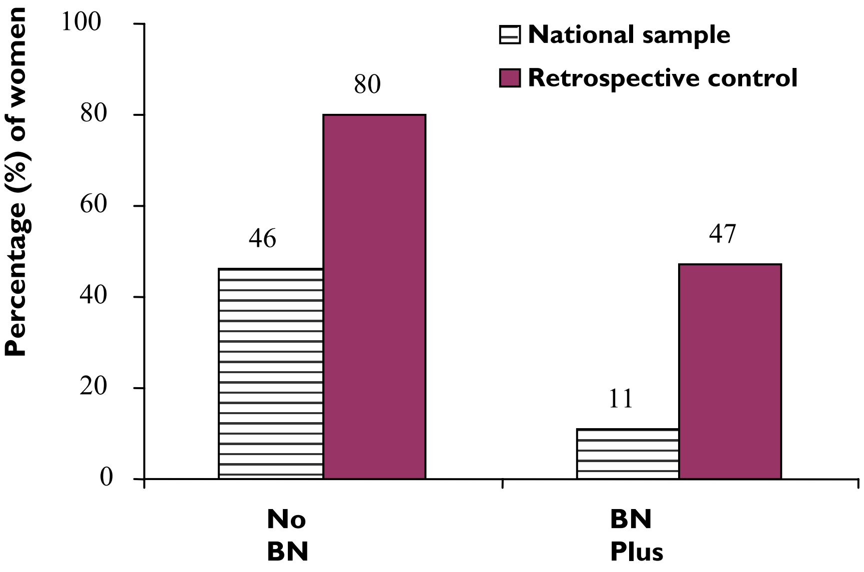
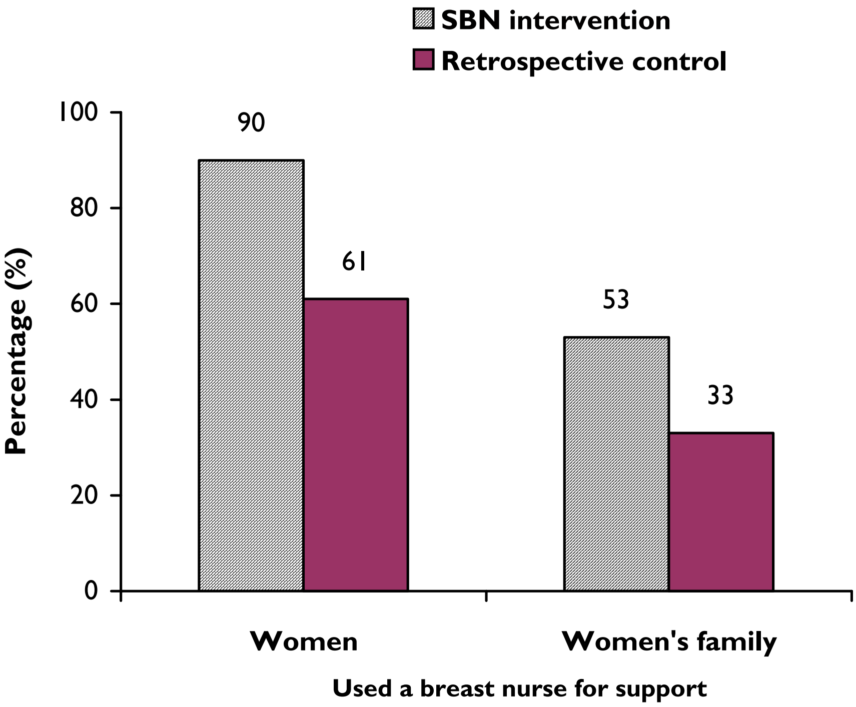


Figure 7.2. The use of a breast nurse for support



Differences between the SBN intervention group and the retrospective control

Breast nurse contact

As shown in figure 7.1, 47% of women in the retrospective control reported systematic contact with a BN (the BN3 plus model). To ensure that a clear distinction is made here, the retrospective control will be reported as seeing a breast nurse (BN) and the intervention group as seeing an SBN.

SBNs played a key support role for women in the intervention group. Significantly more women in the intervention group (90%) recalled using the SBN for support, than women in the retrospective control recalled using any BN (61%, $p<0.0001$). Similarly, women in the intervention group were more likely to report that their families used the SBN for support (53%), compared with the use of a BN by women in the retrospective control (33%, $p<0.0001$).

Information

Diagnosis and Treatment

Women in the intervention and retrospective control groups did not differ in their recall of how they were told about their diagnosis of breast cancer. Most responses were consistent with the recommendations in NHMRC clinical practice guidelines: they were told face-to-face (intervention = 82%; retrospective control = 90%); and the diagnosis was given in a way that was honest, open and frank (intervention = 87%, retrospective control = 92%).

Women in the two groups did not differ in their recall of involvement in decision-making about treatment (Appendix 43), with 82% of the intervention group actively making their treatment decision by themselves or collaboratively with their doctor, compared with 89% in the retrospective control. Although most women in both the intervention (86%) and retrospective control groups (85%) were satisfied with the amount of time allowed to make their treatment decision, about 40% in both groups reported that they were given the impression, that they had to decide about their treatment straight away.

Clinical trials

More women in the intervention group were told about clinical trials (40%) than in the retrospective control group (26%, p=0.003), and more women in the intervention group (18%) actually participated in a clinical trial that in the retrospective control group (10%, p=0.004) (Appendix 44). Of those who were told about clinical trials, about 40% in both the intervention and retrospective control groups went on to participate in a trial (Figure 7.3).

Figure 7.3. Clinical trials information and participation

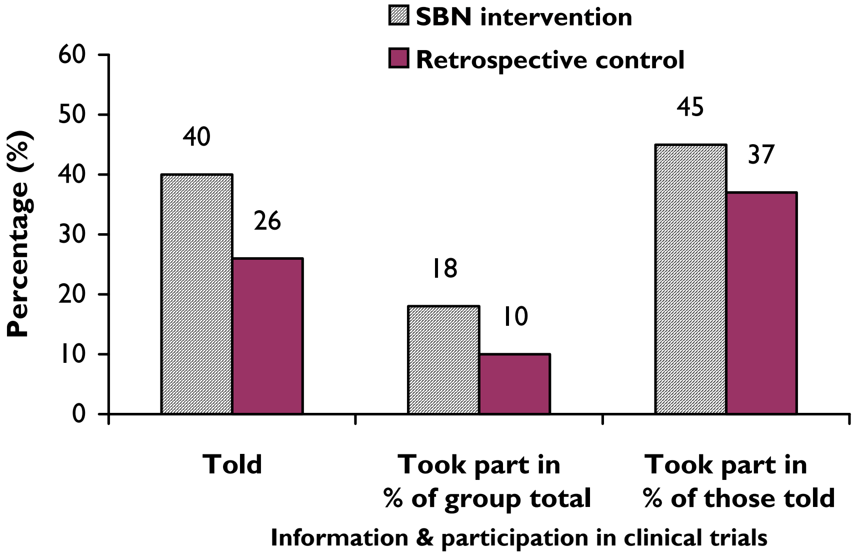
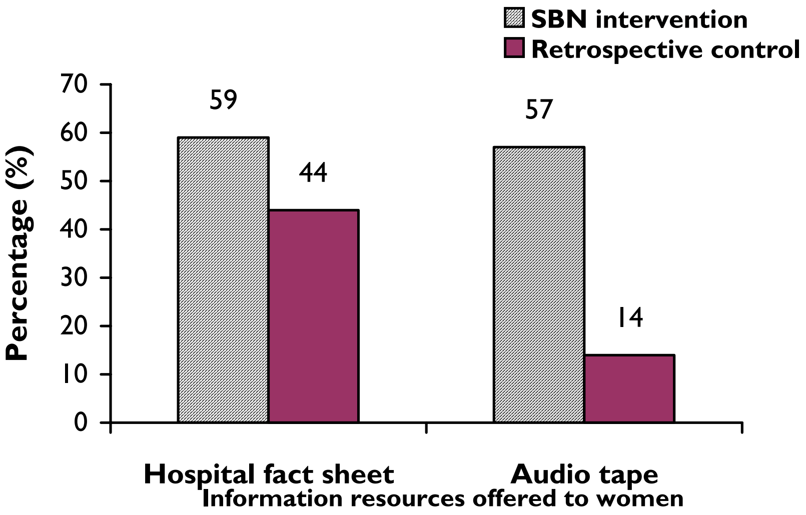


Figure 7.4. Information resources offered to women



Information resources for women with breast cancer

Most women in the intervention (83%) and retrospective control (78%) groups were offered standard information resources (booklet, audio or video tape about early breast cancer) (Appendix 45). Women in the intervention group (59%) were more likely to be offered a hospital fact sheet than women in the retrospective control (44%, $p=0.03$). Furthermore, a significantly higher proportion of women in the intervention group (57%) were offered an audio tape of their consultation than those in the retrospective control (14%, $p<0.0001$) (Figure 7.4).

Satisfaction with information

Overall, 83% of women in the intervention group and 85% of women in the retrospective control group were satisfied with the amount of information they received (Appendix 46). While 81% of women in the intervention group reported that their family had access to as much information as they needed, compared with 72% in the retrospective control, this difference was not statistically significant however.

Treatment

Surgery and hospital stay

Women in the intervention and retrospective control groups did not differ in the type of physical treatments received (Appendix 47). There was a non-significant trend for more women in the retrospective control group to have a mastectomy and for more women in the intervention group to have lumpectomy with radiotherapy. The groups did not differ with respect to either length of stay away from home for treatment (mean 48 days), or for length of stay in hospital (mean 5 days) (Appendix 48).

Side effects

Women in the two groups did not differ in the side effects or complications experienced as a result of breast cancer treatment (Appendix 49), with 35% of the intervention group and 27% of the retrospective control reporting no complications.

Breast reconstruction and breast prostheses

Participants were also asked whether they received an external breast prosthesis or underwent breast reconstruction. A higher proportion of women in the intervention group (17%) than in the retrospective control group (10%) reported that they had had, or had considered having, breast reconstruction (Appendix 50). Fewer women in the intervention group (32%) received an external breast prosthesis than in the retrospective control (47%, p=0.06).

Follow-up care

More than three-quarters of both groups recalled receiving a plan for follow-up care after their last chemotherapy or radiotherapy appointment (Appendix 51). There were no significant differences between the groups.

Practical assistance and support

The intervention and retrospective control groups did not differ in relation to practical assistance for travel and accommodation. Almost all women reported that they received assistance when needed, or else did not need feel they needed it (intervention = 96%, retrospective control = 95%) (Appendix 52).

There were no significant differences observed between the intervention and retrospective control groups regarding women's knowledge of, or use of, the BCSS (Appendix 53).

Overall Support

The vast majority of women in both the intervention and retrospective control groups were highly satisfied with the standard of care they received in general, and the level of support that they and their families received from their treatment team (Appendix 54). Overall 89% of women in the intervention group reported that they were given as much support as they needed, compared with 84% in the retrospective control.

Discussion

The three-group design was adopted to enable the comparison of consumer evaluation of care according to SBN involvement. As detailed elsewhere (Williams *et al.* in review 2000), women in the National sample reported limited contact with any breast nurse, and only 11% had a systematic level of contact across treatment phases (BN3 plus model). Women in the National sample reported more favourable perceptions of both the support and information received where there was evidence of systematic BN intervention.

While only six percent of the retrospective control recalled no access to a BN, less than half of the women in the retrospective control reported access to a systematic BN intervention as part of their treatment. When compared with the National sample, the retrospective control for the Collaborating Centres was more positively evaluated in many aspects of support and information provision. This result was expected, given the selection of these treatment sites as centres of excellence. The data also indicated a high level of satisfaction with overall care, producing a potential ceiling effect, which makes the measurement of positive change more difficult.

When compared with the retrospective control, the perceptions of care of women in the intervention group were also very favourable. Despite the potential ceiling effect, the introduction of the SBN model did produce some differences in women's perceptions of their care.

The "5 in 12" clinical pathway ensured that more women in the intervention group accessed SBN/BN care across treatment phases. More importantly, however, were indications that they made use of this access – women in the intervention group were more likely to report that they actively used the SBN/BN for support for themselves and their families.

The SBN intervention was also associated with more favourable perceptions of information delivery. Women in the intervention group were systematically offered at least one evidence-based early breast cancer resource (written, audio-tape or videotape). This greater access to information about treatment options may explain why more women in the intervention group had either had, or at least considered, breast reconstruction.

Women in the intervention group were also more likely to be offered an audio-tape of one or more of their consultations. Although specific details of the taped sessions were not obtained, the audio-tapes were most likely consultations with the SBN, as the option of taping consultations was part of the SBN protocol (women's evaluation of the usefulness of taping consultations is reported in Chapter 6). The practice of audio-taping consultations is not limited to sessions involving SBNs, however, as women in the retrospective control were already significantly more likely to be offered an audio-tape of their consultation than those in the National control.

The SBN intervention was also associated with an overall higher participation rate in clinical trials. More women in the intervention group were informed about, and participated in a clinical trial, although the true participation rate (the percentage of women who were informed and consented) did not vary. Given the poor participation rate nationally (6%), these results suggest that women need to be provided with adequate information about clinical trials, and that SBNs can be effective in providing this information.

This evaluation confirmed the quality of the Collaborating Centres that enabled the observation of the feasibility of the SBN model of care in stable treatment centres. The evaluation also indicated that despite women's generally positive perceptions of care nationally, a systematic and evidence-based SBN intervention improves information provision and support in a number of ways for women with breast cancer.

Chapter 8: The nature and impact of the specialist breast nurses' psychological care

The evidence-based specialist breast nurse (SBN) model of care aims to improve the psychological wellbeing of women treated for breast cancer. This chapter describes the specific aspects of the intervention provided by SBNs to identify and respond to women's psychological needs (including significant anxiety states and depressive disorders).
It also reports on factors affecting the SBN model's feasibility as first phase psychological support in Australian breast cancer treatment settings, including an evaluation of its effectiveness.

The history of SBNs in psychological care

Early research on the impact of mastectomy consistently found that rates of anxiety and depression among women treated with mastectomy for breast cancer were alarmingly high, with almost half of women affected in the first 12 months post-diagnosis (Ray, 1977; Maguire, 1978). Yet some studies report that only 20-50% of psychologically distressed cancer patients are identified and treated appropriately (Maguire *et al.* 1986; Ford *et al.* 1994). In their review, Hall and Fallowfield (1989) concluded that advances in surgical techniques alone, such as the development of breast conserving surgery, had not made a significant impact on these levels of psychological disturbance, as also evidenced in the recent study by Kissane et al (1998) which reported that more than 40% of women with early breast cancer experienced a psychiatric disorder.

The SBN model aims to improve the psychological care of women with breast cancer. The findings of the randomised control trials, described in Chapter 1, have been encouraging. In at least two studies the SBN model of care has seen a reduction in women's levels of distress (Watson *et al.* 1988, McArdle *et al.* 1996). The SBN's direct intervention alone has not been effective in treating women with more severe psychological difficulties (eg an anxiety disorder or major depressive episode). It has, however, led to improved detection and referral levels, enabling woman to gain access to mental health professionals (Maguire *et al.* 1980).

Psychological support in the SBN project

The core activities of the present SBN model which are most relevant to the psychological care of women with breast cancer include:

- providing information in relation to psychosocial issues;
- providing supportive counselling when needed; and
- ensuring the early detection and referral of women with significant psychological problems to appropriate health care providers.

These activities are set out in the clinical pathway (Figure 2.1) following the evidence-based recommendations in the National Breast Cancer Centre's (NBCC) *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer* (NHMRC NBCC, 2000). The SBNs attended the brief training course described in Chapter 3. The training included a review of evidence-based psychological treatments reported in the guidelines, as well as interactional skills training focusing on implementing the recommendations in key areas of care.

The SBN's role is to assess and respond to:

1 Factors present at diagnosis that indicate a woman may be at risk of developing impairing psychological reactions to the diagnosis and treatment of cancer

A number of factors have been found to identify women who are more at risk of developing significant psychological concerns and thus may need more assistance (such as those who are younger or who have a psychiatric history (Turner *et al.* 1998). SBNs assess and record the risk profile of women at their first visit (Appendix 55) and use this information in planning the initial intervention.

2 Psychosocial responses of all women to key clinical events

There are a number of key clinical events likely to make significant psychological demands on all women. For example, diagnosis is likely to be distressing for almost all women, as is the prospect of treatments such as mastectomy or chemotherapy.

3 Symptoms of psychological disturbance during the treatment process

Psychological responses to the diagnosis and treatment of breast cancer are complex and changeable. Regular screening is recommended throughout a woman's treatment for breast cancer for her level of emotional reaction and concerns. The SBN clinical pathway included this at all scheduled contacts. Where a woman was assessed by the SBN as being psychologically at risk, it was recommended that the SBN consult with, and/or refer women to, an appropriate mental health professional. SBNs used their hospital's services for this.

Measures and observations

Patient logs

As described in Chapters 2 and 4, SBNs recorded details of consultations with each woman and the woman's psychological risk factors and concerns in the patient logs. Coding of needs included codes for mention of psychological symptoms, body image or sexuality concerns, and relationship concerns. Interventions coded included provision of information, counselling, liaison with other health professionals (eg offering/arranging referral) and physical treatment issues (eg wound care).

The General Health Questionnaire

Women completed the 12-item version of the General Health Questionnaire (GHQ-12) (Goldberg, 1972; Goldberg *et al.* 1988) which asks about psychological symptoms over the previous few weeks. This self-report questionnaire, previously validated in medical populations, identifies women who were more highly distressed and may have benefited from a more thorough assessment or intervention. It does not attempt to provide a specific diagnosis of anxiety or depression. As such, it reflects the need for SBNs to be able to identify different levels of distress, rather than conduct detailed mental health assessments. The GHQ-12 was completed independently by the women and returned directly to the NBCC by post at two and six months post-diagnosis. The SBNs remained blind to this evaluation.

The dichotomous scoring method was used for each item (0, 0, 1, 1), providing a total scoring range of 0-12. Following Goldberg's (1988) recommendation, the cut-off score used to indicate a likely anxiety/mood disorder was increased to 4 or more to control for the influence of physical symptoms attributable to disease or treatment effects. In other words, scores were interpreted as follows: 0/1 (no/low level of need), 2/3 (borderline status) and 4+ (high level of need and likely disorder).

Satisfaction questionnaire and telephone interview

Women answered additional questions about their psychological wellbeing in a brief self-report questionnaire accompanying the six month GHQ, and as a part of the 6-12 month telephone interview. The questionnaire asked whether the woman received enough emotional support from the SBN, and whether she felt she needed and whether she received a referral to a professional counsellor from the SBN.

In the 6-12 month telephone interview conducted for both the intervention group and the retrospective control group, five questions were asked about key symptoms of anxiety and depression. These were chosen to indicate a high level of need but not to provide a diagnosis of anxiety or depression. The women's recall of referral patterns was also recorded in the interview.

Initial psychosocial risk factor profiles

SBNs assessed psychosocial risk factors for all women at their first consultation (Appendix 55). The most frequent risk factor was having children under the age of 21, affecting 34% of the intervention group. Approximately 14% of women had a psychiatric history, and a similar proportion reported economic difficulties and the presence of other ongoing stressors. Taken together, 70% of the women reported low risk or no risk, with the remaining 30% reporting multiple risk factors at diagnosis.

Interventions initiated by the SBNs on the basis of risk factor profiles

The SBNs considered the women's psychological risk factors in their interventions (Appendix 56). As described in Chapter 4, four categories of intervention were coded from the logs: providing information; counselling; liaison; and physical treatments. Data were examined within each scheduled appointment to determine if SBNs provided different types of intervention according to assessed psychosocial risk.

In a further series of analyses, there was a trend for SBNs to spend more time with women who had multiple risk factors, but the only significant difference was detected at follow-up 2 (F = 8.6, df =2, p=0.0002). The Scheffe post hoc comparison test (Cook and Campbell, 1979) indicated that women with multiple risk factors had significantly longer consultations (mean = 50.3 minutes, SD = 41.6) than either the one-risk (mean = 33.1 minutes, SD =41.6) or the no-risk group (mean = 31.4 minutes, sd=20.0). A related finding was that more women with multiple risk factors (78.5%) attended the follow-up 2 appointment as a face-to-face appointment than women with only one risk factor (60.7%) or no risk ractors (65.7%) ($\chi^2 = 6.1$, df =2, p=0.047).

In summary, the SBNs demonstrated a trend to adjust their interventions according to the level of psychosocial risk they had assessed the women to have, but in practice these differences were not statistically significant until the second follow-up appointment.

Statistical note: To minimise the risk of chance findings in these analyses, given the number of comparisons (five appointments and four interventions in each), an overall type 1 error rate of 0.05 was allowed for analyses for each of the five scheduled appointments (Cook and Campbell, 1979). This required differences in any intervention to be <0.0125 to be considered statistically significant.

There were no significant differences at any time in the amount of counselling, information or treatment that SBNs provided to women at different levels of assessed psychosocial risk. There were, however, differences in liaison with other health professionals at three of the scheduled appointments, one of which was statistically significant. At follow-up 2, women who had no psychosocial risk factors received less liaison than women with one or more risk factors ($\chi 2 = 10.9$, df = 2, $p < 0.005$).

Detection of women with high distress

Two-month GHQ-12 scores

Psychological morbidity at two months

The GHQ-12 questionnaire was analysed to determine the range of scores and the percentage of women experiencing high levels of distress. The average GHQ-12 score was 3.2 (SD = 3.6) and the median was 2. More than a third (35.4%) of women had scores greater or equal to 4, indicating that they were likely to have a psychological disorder (Appendix 57). Encouragingly, 44.8% of women were in the range of scores indicating no psychological symptoms. The remaining women scored in the borderline range.

Impact of initial psychosocial risk factors

The GHQ-12 scores were also examined to see whether the women's initial psychosocial risk factors (assessed by the SBN at diagnosis) statistically influenced their two-month GHQ-12 scores. The results indicate that 49% of the women who recorded multiple risk factors went on to score in the high range on the GHQ-12. This is significantly greater than those with no risk factors (26% of whom scored in the high range), and equal to those with one risk factor only ($\chi^2 = 11.7$; df = 4, p = 0.02). These findings are difficult to draw conclusions from, particularly in the absence of a control group. The results are as expected in that those more at risk actually developed higher levels of distress, but it is difficult to assess the impact of the SBN's intervention on this.

Identifying high GHQ-12 scorers

The clinical pathway requires SBNs to be alert for women experiencing high levels of psychosocial need, and to intervene accordingly. Data from the patient logs were examined to determine if the SBNs had independently recognised the women who were GHQ-12 high scorers (the SBNs were blind to the GHQ-12 results) (Appendix 58). The logs were examined to identify if the SBNs had noted, firstly, that the women had high levels of anxiety, depression or psychological distress ("psychological symptoms") and secondly, any type of psychological difficulty including relationship problems, sexual or body image difficulties ("any psychological need").

Since the GHQ-12 was assessed at two months post-diagnosis, the main emphasis was on patient log data at follow-up 1 (the closest time point to the GHQ-12 period) and follow-up 2. The entries for scheduled and patient-initiated consultations were examined separately. Statistically, because of the multiple comparisons in the analyses, the type 1 error rate was controlled by establishing a family wise error rate of 0.05 for each time point, requiring significance at $p < 0.025$ for the comparisons within time points (Cook and Campbell, 1979).

At follow-up 1 the SBNs had noted "psychological symptoms" as a need for approximately one half of the women who were high or borderline GHQ-12 scorers, and "any psychological need" for 58% of the high or borderline groups. There was a strong trend for the SBNs to note fewer psychological needs for the low GHQ-12 scorers than either the borderline or high GHQ-12 groups.

At follow-up 2 the SBNs noted that 57% of the high GHQ-12 group had high "psychological symptoms" needs, and 71% of the group had "any psychological need". This was statistically greater than the needs reported for either the borderline or low scoring groups.

The SBNs were less likely to record psychological needs for high GHQ-12 scorers in consultations initiated by the women (Appendix 59). The SBNs recorded "psychological symptoms" as a need for only 29% of those who were high scorers, and "any psychological needs" for 66% of high scorers. In these non-scheduled consultations SBNs did not statistically differ in their reporting of psychological needs between high, borderline or low GHQ-12 scoring women.

There was no evidence that consultations varied in length of time taken, or in the proportion which were face-to-face (rather than by telephone), as a function of GHQ-12 scores.

Six-month GHQ-12 scores

The average six-month GHQ-12 score was 2.4 (SD = 3.5) and the median was 0. These scores were significantly lower than at two months (Wilcoxon $Z = -4.1094$, $p < 0.0001$). The percentage of women in the low GHQ-12 scoring range increased from two months to six months, and the percentage of women in the borderline group decreased. More than a quarter of women scored in the high range at six-months, but this was also a lower proportion than at two-months.

There was, however, little or no change in the percentage of women with very high scores. At two months 16% of women scored 7 or more on the GHQ-12 and at six months there were 18.9% scoring 7 or more. Additionally, 56% of the cohort of very high scoring women at two months continued to score 4 or more at six months, including 38% who remained at levels of 7 or more.

Of the group of women whose scores were 4 or more on the GHQ-12 at two months, 46% continued to score at this high level at six months.

The six-month GHQ-12 scores were analysed to determine if women receiving ongoing treatment (such as chemotherapy) were more likely to have high scores. Partial correlations calculated between treatment variables and the six-month GHQ-12 scores (controlling for two-month GHQ-12 scores) showed no significant relationship. That is, the psychological distress at six months was predicted by women's distress reported at two months, rather than by any ongoing treatment.

Patterns of referral

As indicated in Appendix 24 and Table 8.1, the rate of referral recorded by SBNs was low compared with the number of women scoring highly on the GHQ-12. Three reasons can be considered for this. Firstly, SBNs may not have been able to detect the full level of women's distress and therefore did not offer referrals. Secondly, while being aware of women's level of distress, SBNs may have been unable to access services for a referral. Thirdly, women may have been unwilling to accept referrals.

Access to any mental health services, and particularly to mental health professionals with specific expertise in oncology, was a major limitation in this demonstration project. Difficulties in referral ranged from a complete absence of services, to access only to a generic mental health worker, to a seven-week wait for specialist services such as clinical psychology or psychiatry. No SBN reported having access to mental health professionals to provide ongoing psychological supervision or case review, despite its promise as a more cost-effective use of specialist time in the face of potentially large referral numbers.

Table 8.1: Percentage (%) of women referred to psychosocial professionals, by treatment phase

Referral agent	Treatment phase Diagnosis %	Pre-operative %	Post-operative %	Follow-up 1 %	Follow-up 2 %
Social worker	6.3	16.0	11.8	8.9	2.1
Counsellor, psychologist or psychiatrist	0.8	2.9	0.16	3.8	3.4

There was some indication from data collected as a part of the six-month questionnaire and the 6-12 month telephone interview that women were reluctant to take up referrals when available. At six months 51% of women reported that the SBN had offered referral to a social worker, 36% to a counsellor/psychologist/psychiatrist and 33% reported that the SBN had offered to organise further professional counselling. These data indicate that in many instances women may not have accepted referral offers. However, results from the six-month questionnaire did indicate that 12.8% of women felt they needed more emotional support from the SBNs.

Telephone survey of the intervention and retrospective control groups

Data from the telephone interviews indicate similar levels of distress to the GHQ-12 scores. Approximately a third of women in the intervention group experienced a key symptom of anxiety, and a little more than half reported a key depression symptom. In total, 33% of women in the intervention group reported more than one key symptom, while 22% reported three or four key symptoms. No statistical differences were detected between the prevalence rates of these symptoms in the intervention group and in the retrospective control group. However, there was a non-significant trend to indicate that the intervention group, experienced distress which was less mild, but more significant. This is consistent with earlier studies that found that SBNs are more effective with women with minor adjustment problems and distress than with those with major mood disorders.

Figure 8.1: Detection of women's psychological concerns by the SBN at follow-up 1 and follow-up 2, by their GHQ-12 scores

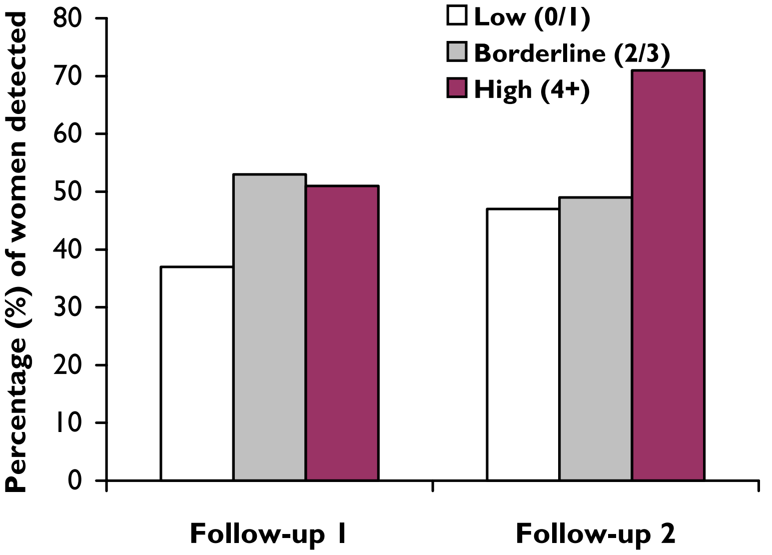
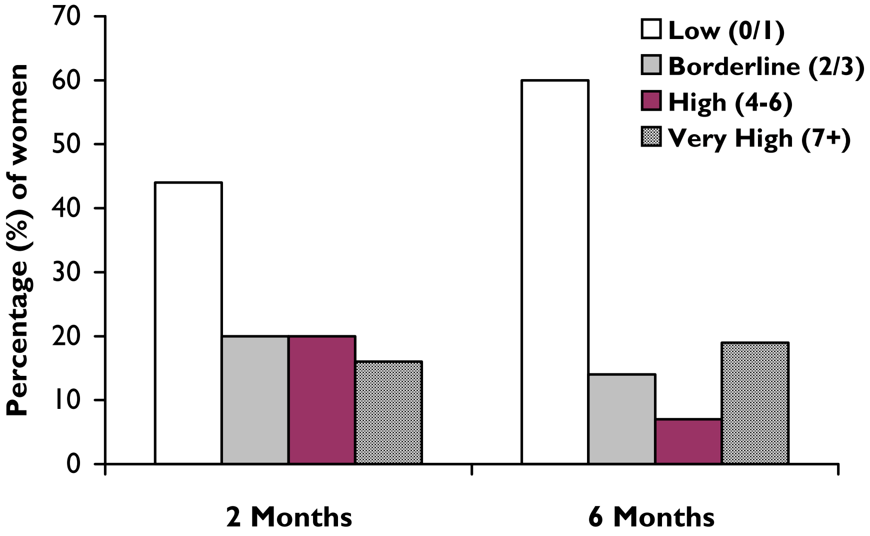


Figure 8.2: Distribution of women's GHQ-12 scores at 2 and 6 months



Overall, responses from the telephone interviews do not indicate any differences between the control and intervention groups in terms of the number of women who saw trained mental health professionals or social workers. Of the women interviewed in the retrospective control group, 12% saw a social worker and 15% saw a counsellor, psychologist or psychiatrist, while in the intervention group 14% saw a social worker and 13% saw a counsellor, psychiatrist or psychologist.

Conclusions

The results of the psychological aspect of the project indicate that the SBN model is promising in a number of ways for Australian practice. Firstly, there is evidence that with the aid of clinical practice guidelines and brief training, SBNs can adhere to a psychosocial protocol to assess risk, and respond accordingly. This is important, as none of the SBNs had mental health nursing training. There was some evidence, too, that the SBNs adjusted their intervention in the later treatment phases, in order to provide greater time for women at higher psychosocial risk.

The SBNs demonstrated some success in identifying women with clinically significant levels of distress. However, their ability to do so was limited in two ways. Their detection rate was better if the need reported was general ("any psychological need") rather than specifically about distress ("psychological symptoms"), and if the woman was seen within the scheduled consultations rather than in consultations initiated by women. This points toward the need for better training in identifying and responding to psychological cues (regardless of the presenting problem), the need for a protocol that covers any consultation, and the use of screening strategies to enable the SBNs to identify women with high levels of distress more successfully.

The project also identifies gaps in the provision of specialist mental health services. Significantly, a key feature in the majority of the randomised control trials was active involvement of psychiatrists or psychologists in supervision, or their availability for referral. In this project these services were either lacking or difficult to access, requiring the SBNs to operate at skill levels which their training does not support. If SBNs are to play a role in reducing psychological morbidity they must have access to these services for case review and referral.

In summary, the GHQ-12 scores indicated that:

- at two months, around the conclusion of the intervention, more than one in three women had GHQ-12 scores indicating high levels of distress;
- at six months, this dropped to one in five;
- a total of 46% of women were high scorers at either time point; and
- approximately 15% of women at both time points scored very highly. This included a small group of women who continued to have very high levels of psychological distress for the survey period.

From the patient log data, there is evidence that SBNs detected between 59% and 72% of women who were high scorers on the GHQ-12 at two months. There was, however, only a low rate of successful referral to specialist mental health professionals, with indications that many high scorers at two months remained distressed at six months. This is due to a combination of factors, possibly including the women's reluctance to accept a referral.

Overall there is evidence that SBNs are effective in detecting the psychological needs of women with breast cancer. There is some evidence that while the intervention was more effective with mild distress it was not sufficient to prevent overall levels of morbidity. Better supervision, training and back-up from mental health services is strongly recommended to improve these outcomes.

Chapter 9: Evaluating the economic feasibility of the specialist breast nurse role

Introduction

This chapter investigates key factors to be considered when examining the economic feasibility of the evidence-based specialist breast nurse (SBN) role. The breadth and time frame of the SBN demonstration project means that its main empirical contribution to any discussion of economic feasibility is illustrative rather than exhaustive. This chapter generates economic information on the resource implications of the SBN model. Further longitudinal economic data on the costs and benefits of the SBN model are required to assist decision-makers in setting priorities for breast cancer care. A discussion of adequate methods for such comprehensive, long-term, economic evaluations of the SBN model of care is also initiated here.

Specifically, this chapter addresses three questions:

- How can the economic feasibility of the evidence-based SBN model of care be assessed?
- What were the financial costs of implementing the SBN model of care in the demonstration project?
- How did the SBN model of care affect resource utilisation in one breast clinic?

How can the economic feasibility of the evidence-based SBN model of care be assessed?

For every choice made about the provision of health care, we forgo the opportunity to use those resources for some other worthwhile purpose. This is known as “opportunity cost”. The establishment of a SBN model of care requires judgements to be made about its economic feasibility, and ultimately a decision made regarding the question, “What is the opportunity cost of the resources used for a SBN position?”

Two principles are considered in the process of evaluation: efficient resource allocation and equity. Does the SBN model of care represent efficient resource allocation? The question arises as to whether the implementation of the SBN model represents an efficiency gain (value for money) compared with current practice. Efficiency of health care systems can be achieved through systematically comparing the costs and benefits of the full range of health care activities and then choosing those programs that deliver the greatest benefits. In this way, efficient resource allocation is a means by which the health of the community (or patient group) can be maximised.

However, allocating resources is seldom a matter of simply choosing efficient programs. Equity of resource allocation-in terms of who bears the costs and who gains from the consumption of health care-is also a desirable economic goal. Just as choice is inevitable in health care, so are the trade-offs between efficient and equitable uses of health care resources.

Tailoring economic evaluations

Choosing programs whose benefits exceed their opportunity cost maximises the amount of “health” produced by the health care sector and minimises costs. An economic evaluation systematically compares the key costs and benefits of competing health care programs to enable such judgements to be made. One of a set of techniques may be employed, including cost-benefit analysis (CBA), cost-effectiveness analysis (CEA) and cost-utility analysis (CUA) (described in Table 9.1).

The appropriate economic evaluation technique depends on the question being addressed. If the question is whether to allocate resources to a program or whether to allocate more or less resources to it, the question concerns allocative efficiency. Allocative efficiency describes how best to distribute resources across competing programs. Cost-benefit analysis is typically used to determine allocative efficiency, although within the health care sector cost-utility analysis can also answer this question.

Often in health care, a decision has already been taken to fund a program and the question is how best to pursue a particular objective. Cost-effectiveness analysis deals with technical efficiency and seeks to answer the following questions: “Given that it has been decided that an objective is to be achieved, what is the best way of doing so?” and “What is the best way of spending a given budget?”.

The fundamental question for the SBN model of care is whether to allocate more resources to expand the program. At first glance, this is primarily a question of allocative efficiency, addressable either by CBA or CUA. For a variety of reasons, the SBN model of care does not fit neatly into the economic evaluation framework, and neither CBA nor CUA is likely to provide an immediate or useful answer to the resource allocation question. There are important issues to consider, for example, about who benefits from the model of care, the nature of those benefits and whether the outcomes can (or should) be reduced to a single index of effectiveness.

Who benefits from the SBN model of care?

The question of who benefits from the SBN model of care, and how, is every bit as important as counting the costs of achieving those benefits. The SBN intervention is designed to improve the psychosocial care of women with breast cancer. Clearly, women are the main intended beneficiaries, but their families may also benefit from the SBN intervention (Chapter 3), and there is also evidence that the presence of a SBN benefits the treatment team (Chapter 5).

What is the nature of the benefit?

Economic evaluation focuses on the final consequences of a service and often ignores utility derived from its process and quality. In the case of the SBN intervention, however, the focus ought to be on the process and quality of service because it is the process of delivering care that best reflects the model’s immediate objectives. Additionally, very few economic studies of health care programs specifically address how these benefit health care professionals themselves as part of the process of delivering better care overall. In the long run, it is expected that more tangible health gains will accrue to patients, but these could not be evaluated within the life of this project.

It makes little sense to derive a narrow measure of efficiency (as implied by a cost-effectiveness ratio) when the real impact of the SBN intervention is much broader in respect of who benefits, and how. In the long term it would be desirable to conduct a comprehensive economic evaluation based on detailed evidence regarding the psychosocial and physical health effects of the SBN model. This type of evaluation is discussed later in this chapter. In the short term, however, the aims of this part of the SBN project were:

- to generate economic information on the resource implications of the SBN (ie the initial financial costs to employ a SBN); and
- to illustrate one method of examining the resource implications of the SBN model of care.

Table 9.1: Techniques of economic evaluation

Cost benefit analysis (CBA) looks at one or more programs in terms of their costs and benefits. This requires all costs and benefits to be valued in a commensurate unit, such as money. CBA is used to compare a wide range of programs, both within and beyond health care. Funds are then allocated to those programs that maximise benefits. In practice, the monetary valuation of benefits in health care is difficult. Placing a dollar value on saving life or relieving pain and suffering is never straightforward. Two approaches are used to assign monetary values to outcomes:

- The **human capital approach** values health benefits in terms of improvements in an individual's productive worth to society. The benefit lies in getting people back to work sooner than would otherwise be the case. This method has inherent problems, particularly if the benefits are equated with earnings. The human capital approach suggests that the benefits accruing to certain groups in society, such as women working at home, unemployed people, or older people, are less valuable than other, high income groups in society. Not surprisingly, the human capital approach is regarded as inequitable.
- The **willingness to pay (WTP)** approach values health benefits in terms of what an individual is willing to pay for a health gain. This approach also has some inherent problems. Firstly, willingness to pay is affected by ability to pay. Again, lower income groups in society are less able to afford health care. The WTP approach suggests that the benefits of health care are higher for higher income groups. Secondly, people are not familiar with the concept of willingness to pay for health care and may find it difficult to translate health gains into dollars.

For all the reasons listed above, the cost-benefit approach is rarely used in health care as it tends to ignore equity considerations at the expense of efficiency goals.

Cost-effectiveness analysis (CEA) does not require health benefits to be valued in monetary units and hence avoids many of the problems associated with CBA:

- Benefits are measured in terms of health effects such as life years gained, clinical events avoided or some other natural unit of outcome.
- Programs are then compared in terms of the ratio of cost to unit of health effect whereby the alternative with the lowest cost-effectiveness ratio is most efficient,

The relative simplicity of CEA (compared with CBA) comes at a price. The measure of outcome is unidimensional and must relate to the objective/s of the program. Hence programs with different objectives and different units of health effect cannot be compared in terms of their cost-effectiveness.

Cost utility analysis (CUA) extends CEA by combining quantity and quality of life into a multidimensional unit of effect (such as, the quality adjusted life year (QALY). There are several measurement techniques used to capture individuals' preferences for health. Typically, these preferences are expressed on a scale from zero (worst possible health state) to one (best possible health state).

The resultant cost per QALY ratio can be used to assess the worth (allocative efficiency) within a clearly defined health budget. All other things being equal, the alternative with the lowest cost-utility ratio is most efficient.

What were the financial costs of implementing the SBN model of care?

The financial costs of the SBN model were estimated for each site. The Award pay rate (plus an allowance for "on costs" such as superannuation, annual and sick leave and workers compensation) was multiplied by the contracted hours worked by the SBN. For many reasons, the financial cost does not necessarily approximate the opportunity cost (that is, the benefits forgone from using those resources for another worthwhile purpose) of employing SBNs. This is discussed further in the results section.

The financial costs of SBNs vary according to their employment contracts (working full-time or in a part-time/shared work arrangement), as well as the treatment setting. The monthly cost of the SBN by treatment site ranged from $2635 per month for a half-time position, through to $5500 for a full-time position (Appendix 60).

Assessing the resource implications of the SBN model of care

One of the challenges for an economic feasibility study examining the SBN role is to identify the immediate and final effects of the role on outcomes. As discussed above, much of the immediate impact of the model is on the process of health service delivery. SBNs' work has the potential to influence health service utilisation within the hospital-based breast clinic, in acute care services within the hospital itself, and in home and community services. This project provided an opportunity to observe SBNs in their work and to assess the immediate implications of the model of care on the utilisation of existing health service resources.

Designing an observational study such as this produces a number of challenges. These include:

- the need for controls, so that valid comparisons can be made between services with and without SBNs;
- meeting the concerns of teams and institutions regarding observation; and

- ensuring a balance is achieved in terms of protecting the ethical concerns of those being observed (eg balancing the ethics of withdrawing the SBN service for observational purposes with the need to justify the development of the SBN model of care).

Within the demonstration project, the opportunities to conduct such an observational study were limited. The most readily observable arena in which the SBN may affect resource utilisation was an outpatients' clinic. For this reason a breast clinic was selected as an illustrative case study. The methods applied in this case study could be used in future economic evaluation studies in this area.

The breast clinic at the Women's Health Centre, Royal Adelaide Hospital agreed to participate in the observational study. This clinic has a long established position similar in many respects to the evidence-based SBN model of care, and it was felt that an evaluation of that role, including economic evaluation, was important.

The protocol for the observational study involved three steps:

1 identifying the resource inputs to the breast clinic;

2 observing the operation of the breast clinic and measuring the resources consumed in the absence of the SBN (the "without SBN" scenario); and

3 observing the operation of the clinic and measuring the resources consumed with the SBN present (the "with SBN" scenario).

The difference in resource utilisation between the "without SBN" and "with SBN" observations approximates the incremental effect of the SBN on resource utilisation within the clinic. The direction of any change in costs requires careful examination. An increase in costs may mean that previously unmet needs are being met as a result of the SBN intervention. Alternatively, a decrease in costs could indicate potential efficiencies to be gained from SBNs. In this case study, differences in resource utilisation occurred in the way in which resources were deployed, rather than in the total quantity of resources consumed. In this case, attaching dollar values to the measurement of resources adds nothing to the results. Therefore, the cost analysis focuses on changes to the mix of resource inputs into the breast clinic.

An initial visit was made to the Adelaide breast clinic in February 1998, in order to observe its functioning and identify the resources consumed in the care of women with breast cancer. A detailed description of the clinic is provided below.

The output of this initial observation was used to generate a data recording sheet for the "without SBN" and "with SBN" observations. The data sheets recorded the amount of staff input (hours worked) into the clinic (by occupational category) and documented the specific resource inputs for each patient seen at the clinic. The primary aim of the observation study was to record the amount of time spent by clinical staff with breast cancer patients participating in the SBN project. In this way, any changes in the composition of clinical staff and the amount of time spent with women during consultations due to the presence or absence of the SBN could be measured.

To achieve this aim, a taxonomy of patient type was developed to direct research towards those women participating in the demonstration project. Given that the observer (the data manager for the breast clinic) could not observe more than one consultation simultaneously, this provided a practical method for classifying patients. A minimum amount of information was recorded for all breast clinic patients (such as which staff were involved in the clinical consultation, and any diagnostic procedures performed). Additional information, such as the duration of the consultation and the attitudes of other staff members to the absence or presence of the SBN, was collected for those women recruited into the SBN project (Type A patients).

The taxonomy of patient type was as follows:

Type A = New patients – women who have symptoms indicative of a malignancy, and who may require surgical intervention.

Type B = New patients – women who have symptoms not indicative of a malignancy, and who are managed conservatively.

Type C = Former clinic patients – women undergoing further diagnostic assessment and surveillance (this may include a small number of post-operative patients). Only patients who would have been seen by the SBN as part of routine follow-up have been included in this category.

Type D = Patients referred for breast reconstruction, breast reduction or the replacement of breast implants (given medical indication).

Type F = Other

Additional information was sought from the clinical staff for each clinical consultation, via a short questionnaire. This was in order to assess the attitudes of the clinical staff to the presence or absence of the SBN, the impact this had on their interaction with the women, and the duration of the consultation (Appendix 61).

The “without SBN” assessment involved observation and data collection over four days (12, 16, 19 and 23 March 1998). The “with SBN” phase of the study was conducted in a series of two stages. Stage 1 involved observation and data collection over four days (29 June, 2, 6 and 9 July 1998) and this was repeated over another four days (20, 23, 27 and 30 July 1998).

Costing case study - the breast clinic, Women's Health Centre, Royal Adelaide Hospital

The breast clinic is an outpatient clinic operating three times a week from the Women’s Health Centre at the Royal Adelaide Hospital. The Thursday morning clinic is a dedicated breast clinic. It consists of a reception area, a large central waiting area, a meeting room, a blood-taking room, and six consultation suites divided into consultation rooms and examination rooms. Radiology occupies four rooms, and there is a general health promotion unit at the end of the patient waiting area. The SBN’s office is also located within the clinic.

Diagnostic investigations are carried out on site-including clinical examination, mammography, ultrasonography, stereotactic localisation, ductogram, fine needle aspiration, core biopsy and venepuncture. The results of the triple assessment are given to the patient on the same day, with the exception of core biopsy (which usually takes 24 hours for the pathology results to be ready) and blood results. Chest X-rays are performed outside the clinic and are available on the same day. Other procedures performed are doppler testing for tram flap breast reconstruction. The radiology department in the Women’s Health Centre is also responsible for X-raying breast tissue specimens sent urgently from the operating theatre (while operation in progress).

Apart from diagnostic services, the clinic also offers a multi-disciplinary approach to the management, follow-up and review of patients. Assessment for familial risk and referral to a geneticist are available when appropriate. The SBN offers information and support for women and their families undergoing treatment for breast disease and breast surgery.

The clinic accepts symptomatic women referred for further investigation of breast symptoms, or asymptomatic women referred for investigation of abnormal diagnostic or screening findings. Women can be referred for breast reconstruction, breast reduction for medical reasons and removal and replacement of breast implants for medical reasons. Referrals are usually received from breast screening services, general practitioners, and less frequently from other hospital departments. Women are not prohibited from attending the clinic by any geographic boundaries.

Identifying staff inputs into patient care

Table 9.2 summarises staff involved in the operation of the Adelaide breast clinic. The table records the staff present during the clinic, not full-time equivalents.

Organisation of the Thursday breast clinic

The clinic commences at 8.30am and finishes when all patients have been seen (approximately 1pm). A receptionist greets the women and completes their paper work. Women who have already been scheduled for a mammogram are requested to sit in the radiography waiting area, while the remainder sit in the main waiting area. A second receptionist acts as a backup when the clinic is busy. The rest of her time is spent preparing for the next day's clinic.

Table 9.2: The type and number of staff involved in the breast clinic

Type of staff	Number of staff
Surgeon	2
Surgical registrar	2
Clinical Registered nurse CN4	1
Registered nurse RN8	2
Enrolled nurse EN5	2
SBN Clinical nurse consultant	1
Radiologist	1
Radiographer	1
Clerical officer	1
Receptionist ASO 2	1 + a backup
Stenographer	1
Interpreters	as needed
Medical students + Midwifery students	3
Volunteer	1

Women having a mammogram are greeted by a hospital “Lavender Lady” volunteer. If a male radiographer is on duty, she will act as a chaperone and sit in during the procedure. Patients are weighed on arrival by the nursing staff and then called by a nurse when the doctor is ready to see them. Each doctor is allocated a nurse for the day. Sometimes an extra nurse coordinates the clinic and acts as a backup for the nurses when they need help (eg taking blood, answering phones, making appointments).

A surgeon sees all new patients, while the majority of former/review patients are seen by a registrar. A nurse escorts the patient into the consultation room and typically remains there while the patient is seen. She acts as a chaperone, provides support to the patient, and assists the doctor with examinations and procedures. She may leave the room to call the next patient and keep the clinic running smoothly. If a mammogram or ultrasound is ordered, the nurse will organise for the next patient to be seen while this is being performed. After the mammogram or ultrasound is finished, the patient is escorted back to the waiting room and will wait to see the doctor again. The radiographer will leave a written report of the results of the mammogram or ultrasound on top of the patient's notes at the nurses’ station, which indicates that the patient has had their mammogram or ultrasound. This patient will be the next person seen by the doctor.

Results

The resource inputs

The operating characteristics of the breast clinic in the “without SBN” and “with SBN” phases of the study are summarised in Table 9.3. For every patient in the “without SBN” group there were approximately two patients in the combined “with SBN” group. While there were some differences in the duration of each clinic and the clinical input (nurse hours) between the “without SBN” and “with SBN” groups (the “without SBN” group is shorter in duration and has fewer nurse hours), this needs to be read in conjunction with patient throughput data. There were fewer of the more time-consuming, Type A patients in the “without SBN” group than in the “with SBN” group (Table 9.4).

"Without SBN" survey of the attitudes and behaviours of clinical staff

A short questionnaire assessed the extent to which clinical staff felt that the absence of the SBN extended the length of a consultation. The results are tabled in Table 9.5.

In the SBN's absence, clinical staff spent an extra 13 minutes with Type A patients, an extra 12 minutes with Type C patients and no extra time with Type B patients. Clinical staff felt that because the SBN was absent, they spent more time providing support or counselling for 36% of patients seen and more time providing information for 26% of patients seen. The additional information mainly concerned details regarding surgery, inpatient management, the harms and benefits of adjuvant therapy, and information on breast reconstruction.

When asked whether they did anything differently because the SBN was absent, clinical staff said that this was true for 34% of their consultations. In almost all cases this meant spending more time with women, in order to provide further information, support and counselling. Seven women were offered resources or referral that would normally have been organised by the SBN.

Table 9.3: Staffing and patient throughput data for the breast clinic, by observation period

	Observation period		
Characteristic	**Without SBN (n=4 clinics)**	**With SBN 1 (n=4 clinics)**	**With SBN 2 (n=4 clinics)**
Total patients	127	119	125
Total clinic hours	15.5 hours	18.5 hours	17.5
Total surgeon hours	21.25 hours	19 hours	19.5
Total registrar hours	20.0 hours	16.5 hours	19.75
Total CN & RN hours	29.25 hours	46.5 hours	45.5
Total SBN hours	0	15 hours	16.5
Total EN hours	20.5 hours	21 hours	26.25

Table 9.4: Number of new patients, by observation period

	Observation period		
Patient type	**Without SBN**	**With SBN 1**	**With SBN 2**
A	8	13	9
B	21	35	24
D	1		3
F	7	2	2
Total new patients	37	50	38
C	19	11	18

Patient type:

A New patients-women who have symptoms indicative of a malignancy, and who may require surgical intervention

B New patients-women who have symptoms that are not indicative of a malignancy, and who are managed conservatively

C Former clinic patients-women undergoing further diagnostic assessment and surveillance (this may include a small number of post-operative patients). Only patients who saw the SBN as part of routine follow-up have been included.

D Patients referred for breast reconstruction or breast reduction.

F Other new patients

Table 9.5: The proportion of patients with whom clinical staff spent more time in the absence of the SBN, and the average additional time per patient

	Additional time spent		
Patient type	**Yes n (%)**	**No n (%)**	**How much longer on average per patient?**
A	7 (88%)	1 (12%)	13 minutes
B	0	21 (100%)	Not applicable
C	13 (68%)	6 (32%)	12 minutes
D	1 (100%)	0	5 minutes
F	0	7 (100%)	Not applicable
Total patients	21	32	Not applicable

Patient type:

A New patients-women who have symptoms indicative of a malignancy, and who may require surgical intervention

B New patients-women who have symptoms that are not indicative of a malignancy, and who are managed conservatively

C Former clinic patients-women undergoing further diagnostic assessment and surveillance (this may include a small number of post-operative patients). Only patients who saw the SBN as part of routine follow- up have been included.

D Patients referred for breast reconstruction or breast reduction.

F Other new patients

Staff composition for clinical consultations and diagnostic procedures performed

During the 56 consultations in the "without SBN" phase of the study, 84% of women were seen by a surgeon, 23% by a registrar, and a nurse was also in attendance in 77% of consultations (some women are seen by both a surgeon and registrar). Nearly 90% of women had a clinical examination. Those who did not were returning to the clinic either for results or for palliative care. Approximately 10% of women had a mammogram and/or a fine needle aspiration biopsy and/or an ultrasound or other procedure.

"With SBN" observation results

"With SBN" survey of the attitudes and behaviours of clinical staff

Table 9.6 documents the extent to which clinical staff felt that the SBN's presence freed up their time.

Table 9.6: The proportion of women referred to the SBN, and the average length of time freed up due to the referral, by patient type

	Characteristic		
Patient type	**Referred n (%)**	**Not referred n (%)**	**Average time freed up, per patient**
A	13 (59%)	9 (41%)	29 minutes
B	0	60 (100%)	Not applicable
C	13 (43%)	17 (57%)	20 minutes
D	0	3	Not applicable
F	0	2	Not applicable
Total patients	26	91	Not applicable

Patient type:

A New patients-women who have symptoms indicative of a malignancy, and who may require surgical intervention

B New patients-women who have symptoms that are not indicative of a malignancy, and who are managed conservatively

C Former clinic patients-women undergoing further diagnostic assessment and surveillance (this may include a small number of post-operative patients). Only patients who saw the SBN as part of routine follow- up have been included.

D Patients referred for breast reconstruction or breast reduction.

F Other new patients

"With SBN" survey of breast nurse consultations

The average amount of time that SBNs spent with women varied according to patient type. The initial consultation with newly diagnosed women was longer than for former breast cancer patients. The median duration of the consultation for type A patient's was 30 minutes, and for type C patient's 10 minutes (Table 9.7).

Of the 34 women seen by the SBN, three received referrals to other health care services. Fourteen women (41%) received additional resources or literature. The literature included a breast cancer information sheet, a Breast Surgery Unit information booklet, a Breast Cancer Support Service (BCSS) brochure, a Tamoxifen booklet, a surgical oncology booklet, the National Breast Cancer Centre's Early breast cancer consumer booklet (NHMRC NBCC, 1996), the *Guide for country patients attending the Royal Adelaide Hospital* and books about cancer. Services included the Cancer Helpline, BCSS and the Patient Assistance Transport Scheme.

For 14 women, the SBN spent time with their partner, family or support person, seven of whom received additional resources or information (such as the *Family History* booklet and a *Guide for the Partners of Women with Breast Cancer* and *I want to help* brochure).

Table 9.7: The average length of a SBN consultation, by patient type

	Characteristic		
Patient type	**Average duration of consultation (minutes)**	**Median duration of consultation (minutes)**	**Standard deviation (minutes)**
A	29	30	14.5
C	22	10	27
Total patients	34		

Patient type:

A New patients-women who have symptoms indicative of a malignancy, and who may require surgical intervention

C Former clinic patients-women undergoing further diagnostic assessment and surveillance (this may include a small number of post-operative patients). Only patients who saw the SBN as part of routine follow- up have been included.

Do SBNs save clinical staff's time?

Overall, the average length of a clinical consultation for each patient (all types) was 19.6 minutes in the "without SBN" period and 17.9 minutes in the "with SBN" period. It is not possible to conclude that this small time saving of 1.7 minutes is due to the input of the SBN. There is sufficient variation in the average duration of a clinical consultation to suggest that this is a chance result. A more interesting question, then, is how clinical staff allocated their time according to patient type.

A comparison of the average and median duration of a clinical consultation in the "without SBN" and "with SBN" phases suggests that clinical staff do reallocate their time in the presence of a SBN. With a SBN present, clinical staff spend 4 minutes more per consultation with Type A patients (women who have symptoms of a malignancy) and about three minutes less per consultation with Type B patients (women who do not have symptoms indicative of a malignancy) (Tables 9.8 and 9.9).

Table 9.8: "Without SBN" results. The average and median duration of clinical consultations for new patients, by patient type

	Characteristic		
Patient type	**Average duration of consultation (minutes)**	**Median duration of consultation (minutes)**	**Standard deviation (minutes)**
A	22	17.5	11
B	17	15	5.5
Total patients	29		

Patient type:

A New patients-women who have symptoms indicative of a malignancy, and who may require surgical intervention

B New patients-women who have symptoms that are not indicative of a malignancy, and who are managed conservatively

Table 9.9: "With SBN" results. The average and median duration of clinical consultations for new and former patients, by patient type

	Characteristic		
Patient type	**Average duration of consultation (minutes)**	**Median duration of consultation (minutes)**	**Standard deviation (minutes)**
A	26	20	17
B	14	12	9
C	14.5	10	9
Total patients	102		

Patient type:

A New patients-women who have symptoms indicative of a malignancy, and who may require surgical intervention

B New patients-women who have symptoms that are not indicative of a malignancy, and who are managed conservatively

C Former clinic patients-women undergoing further diagnostic assessment and surveillance (this may include a small number of post-operative patients). Only patients who saw the SBN as part of routine follow- up have been included.

Discussion

Based on this case study, the presence of a SBN during clinical consultations appears to have an impact on both the duration and nature of clinical consultations. Members of the medical and nursing staff tend to spend more time with women who have symptoms indicative of a malignancy, and less time with those who do not have symptoms indicative of a malignancy. The presence of a SBN also encourages more discussion on matters relating to treatment and inpatient management. In the context of a busy public breast clinic, such small differences in the duration and nature of a clinical consultation are significant. This reallocation of time suggests that clinical staff do change their behaviour, however slightly, in the SBN's presence.

While the results of the Adelaide breast clinic case study are illustrative, on their own they are neither generalisable nor exhaustive. However, the case study is helpful in understanding some of the resource implications of the SBN. It demonstrates that the presence of a SBN may alter the way in which care is given: in this case small changes in the behaviour of clinical staff were observed with effects on the allocation of the most precious resource- time. A more rigorous experimental design is needed to determine the reliability of such a finding.

The question of whether additional resources should be allocated to expand SBN services remains unanswered. Where research resources permit, this decision should be informed by comprehensive economic evaluation. This in turn depends on an evaluation study design which incorporates controls and is therefore capable of estimating the incremental costs and benefits of SBN care. There are also questions concerning preferences of clinical staff, patients and their families for modes of delivery of breast care services. These relate not only to the acceptability of the SBN intervention but also to the degree of choice in breast care services. There are many questions concerning the process of care and the quality of service that can be evaluated from an economic perspective. In particular, it is important to learn whether (and how) patients trade off the costs, risks, benefits and harms of diagnostic and breast cancer treatment services.

Economic evaluation of the SBN model of care warrants a more methodologically rigorous study design than this illustrative case study. In particular, better controls are needed. That is, an assessment should be made of current breast cancer diagnostic and treatment services (without the SBN model of care) and then compared to the alternative (with SBN care in place). It is the difference in costs and benefits between current therapy and the alternative (with SBN care) which defines the incremental economic analyses.

Both the outcomes of this demonstration project and preceding randomised control trials allow health service providers to identify more specifically the main outcomes of the SBN intervention. Well-controlled, longitudinal studies will provide data to underpin a comprehensive evaluation of these outcomes.

Chapter 10: Feasibility of the evidence-based specialist breast nurse model of care

This chapter reviews factors affecting the feasibility of the evidence-based specialist breast nurse (SBN) model of care. Three key questions arise when considering the routine implementation of this model:

- What skills do SBNs need to implement the evidence-based model of care?
- What is a sustainable caseload for SBNs working with this model?
- What ongoing support do SBNs need?

Data are integrated from a number of sources. These include the views of the SBNs gathered via both individual telephone interviews and a focus group (Chapter 5), and a specific health economic study on caseload.

What skills do SBNs need to implement the evidence-based model of care?

The SBN model of care is designed to ensure that women receive comprehensive supportive care throughout all phases of their treatment. This includes providing them with clinical and practical information, emotional support, supportive counselling and referral to other members of the treatment team and support agencies. Evidence reported in Chapter 4 underscores the diversity and complexity of demands placed on the SBN. If the model of care is to be routinely implemented, the following skill base and training for SBN positions need to be considered.

Comprehensive knowledge of breast cancer and its treatments

The SBN clinical pathway was partly derived from evidence concerning the information needs of women during the different stages of treatment for breast cancer (Chapter 1). Central tasks at each treatment phase are as follows.

- At diagnosis SBNs have a key role in clarifying misconceptions and providing more detail about the diagnostic and prognostic issues and information about hospitalisation, travel, accommodation and financial issues may also be discussed.
- Pre-operatively, SBNs focus on psychologically preparing and supporting women for surgery, and informing them about what to expect afterwards.
- Post-operative consultations involve providing an array of clinical information, specifically in relation to wound care and drain management and providing an overview of the next stage of treatment, including adjuvant therapy, breast reconstruction/ prosthesis and clinical trials.
- The follow-up consultations provide an opportunity to discuss the implications of surgical results and prognosis and to prepare women for the next treatment phases.

SBNs must have an appropriate knowledge base to support women through surgery, chemotherapy and radiotherapy. This knowledge base is strengthened by clinical experience in these areas, and requires a sound understanding of current, evidence-based, clinical practice guidelines for the treatment of women with breast cancer.

Communication skills

Providing information

Perhaps the most important skills that SBNs use in implementing the clinical pathway relate to effective communication, both with women and with other health professionals. Effective communication skills are particularly important to ensure that women and their families can readily access information. Both the nature and the amount of information that women seek may alter over the course of their illness. SBNs must assess the amount of information that a woman requires at any given time, and be able to facilitate information provision accordingly.

Providing emotional support

SBNs provide emotional support to women through the stages of diagnosis and treatment. Therefore they must be able to discuss and appropriately respond to each woman's feelings and concerns, and recognize key clinical events during which her support needs may be even greater. SBNs need to assess personally intimate issues, including relationships, sexual functioning and body image. Therefore communication skills-including effective listening skills and collaborative problem solving skills-are essential.

Psychological support and screening

The SBN model of care also aims to ensure that women with breast cancer receive adequate psychological support. This includes strategies to reduce the level of distress experienced, and the detection of women with significant symptoms of anxiety and depression who may benefit from referral to a specialist mental health professional.

SBNs are not expected to have the skills of a mental health nurse or other mental health professional. Appropriate skills for the SBN role include knowledge of the risk factors associated with the development of significant psychological problems, and skills to properly assess a woman's risk profile. SBNs must also be able to use risk information in the care they give women. As well as knowledge of risk, SBNs need adequate communication skills to identify and respond to the woman's psychological cues, especially for signs that impairing psychological symptoms are developing.

Responding to cultural needs

A woman's cultural needs, including spiritual beliefs, may be an important aspect of her supportive care. It is important that SBNs acknowledge women's cultural and spiritual beliefs and the impact that these may have on her expectations of care. SBN training should therefore cover skills for discussing spiritual issues and also promote awareness of pastoral care services. It is likely that the SBN will also encounter women whose first language is not English. As these women may have been excluded from the present study, additional research may need to be done to determine how the SBN can be most effective in providing support for such women and their families. Additional recommendations are made in the *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer* (NHMRC NBCC, 2000).

Liaising with other professionals

Informing treatment team members and organising referrals

As the coordinator of supportive care, the SBN must be able to function as the conduit of information from the patient to treatment team members and to facilitate the exchange of information between members of the team. It is therefore important that the nurse can liaise effectively with all members of the multidisciplinary team, in order to improve their knowledge of a patient's progress and needs, and that she can discuss and organise referrals when appropriate.

Peer education

Given that SBNs have training and expertise in the management and treatment of breast cancer patients, they must also be able to act as a resource for other treatment team members. Involvement in education programs and participation in research are important components of the SBN's professional development.

What is a sustainable SBN caseload?

The caseloads maintained by the SBNs in this project (reported in Chapter 4) varied both by site and by the individual SBN. The number of new patients seen by each SBN evolved within each treatment setting. Here, caseload is discussed in terms of its "steady state", that is, the total number of women who are receiving any of the scheduled visits at any time-point. For example, if the intervention lasts an average of 12 weeks and there are two new patients recruited each week, the steady state caseload would be 24 women. The steady state caseload observed in the demonstration project across five sites is summarised in Table 10.1.

The questions that emerge are:

- What is an ideal or workable steady state caseload for SBNs delivering this evidence-based model of care?; and
- What can be done to alter the caseload to help SBNs achieve optimum effectiveness in their role?

The project helps answer these questions by identifying factors affecting the workable caseload.

What affects SBN caseloads?

Rate of new referrals and clinical demand each week

One of the most easily identifiable factors is the rate of new referrals. The rate of new breast cancer referrals to the rural centre, for example, was only half that of the larger urban treatment centres, with an immediate impact on steady state caseload. Each SBN's caseload was also affected by how many non-breast cancer patients or non-project patients seen.

Competing priorities

Competing priorities varied in scope and frequency. In keeping with their senior position, many SBNs provided an educational role for other nursing staff. Non-project administration, inservices and research components all take part of the SBN's time. Within the demonstration project, SBNs were also required to allocate time to activities such as completing logs and attending meetings. Other site-specific demands also emerged, such as travel time in the rural area.

Amount of functional time available

Total SBN time available does not necessarily translate into functional time to see patients. The use of available time will be dependent upon both on the time management skills of the SBN and on the influence of external factors, including the schedules of other team members and competing demands on the women themselves. For example, the time available to see new women at diagnosis may be determined by the surgeons' availability or by the total number of patients attending the clinic that day.

The frequency, duration and length of contact

In addition to the factors identified above, an adjustment to caseload may also be achieved by considering the logistics of the clinical pathway. Such adjustments could include:

- the number of consultations allocated to each woman;
- the timing of the consultations; and
- the duration of each consultation.

The number of consultations and their duration are critical in determining a sustainable long-term caseload. Although the number of scheduled consultations was positively endorsed by both the SBNs and women receiving the care, the SBNs believed that some flexibility was required, particularly for women who were adjusting well or for those returning to rural areas.

Some SBNs also discussed the possibility of extending the contact time to 16 weeks. However, such a change could have significant impact on the steady state caseload, as shown in Appendix 62. Even with two new patients each week, by week 16 the cumulative caseload reaches 32. If the new patient load per week was five, the SBN would face an unworkable caseload of 80 women to monitor at any one time.

Additional communication skills training may assist SBNs to be more time-efficient with consultations, although some modification to the clinical pathway may also be required to achieve this. Other options may include an opt-out approach for the follow-up consultations, giving women an opportunity to decline further scheduled follow-ups if they are coping well.

The time used for project administration or for seeing women with other breast disease could also be reallocated. The additional number of new patients that each SBN could manage per month if she did not see “other” patients is reported in Table 10.1. Again, such a re-allocation would need to be conservative if the same “5 in 12” clinical pathway was maintained, as this equates to an increase of 24 patients in the steady state caseload. The removal of other patients from the SBN’s caseload would have little effect on the amount of time she spent on non-patient related activities such as evaluation, teaching and research.

What, then, is a desirable and sustainable steady state caseload? Assuming that the SBN continues to see each woman for five scheduled sessions, with an average of one extra session initiated by the woman and the period of support lasting for 12 weeks, SBNs would be able to manage a steady state caseload of 36-48 women. This load is maintained by an intake of three to four newly diagnosed women each week. A steady state caseload of this order reflects both the complex mix of direct and indirect care that the SBN must allocate for each woman, and the additional roles that the SBN fulfils for the treatment team (Chapter 4).

Ultimately, SBN caseloads are a matter of professional judgement. To that end, these quantitative data should be read in conjunction with the comments of the SBNs in this project (Appendices 63-64).

Table 10.1: Summary of 'steady state' SBN caseloads, by patient type

	Characteristic		
Site	**Patients with a new diagnosis of breast cancer (average / month)**	**Other patients (average / month)**	**Extra patients with a new diagnosis of breast cancer if "other patients" are not part of the SBN caseload (average / month)**
A	34	14	6-8
B	36	20	8-10
C (rural site)	16	2	1
D1 (20 hrs/wk)	27	32	5-6
D2	49	32	4-8

What ongoing support do SBNs need?

Job satisfaction and burnout

The ceiling for the steady state caseload may also be revealed by burnout among SBNs. Certainly, the emotional demands placed upon SBNs can be considerable, since they deal with women with high levels of fear and significant concerns. This may be alleviated by specific training and professional support, but excessive patient contact can also affect SBNs' own wellbeing. As a result, SBNs may become detached from women's feelings, and increased sick leave or resignations may ensue. Early signs of burnout were identified by SBNs themselves at the height of the case accumulation period, but may have been exacerbated by the additional project demands and by ongoing commitments to non-project patients.

Time management pressures

Five out of seven SBNs in this project reported that day-to-day time pressures of their work were significant. The SBNs felt that the workload had a negative impact on their personal lives as well as on their ability to implement the clinical pathway fully:

> **Interviewer**: Did you feel you had enough time to do your job properly?
> **SBN**: No.
> **Interviewer**: What areas do you feel were compromised as a result?
> **SBN**: My sanity, my quality of life … You try to get as much done [as possible], but it's rushed and … sometimes that leads to communication [being] … not so clear. You think you've arranged something and it wasn't quite arranged and that sort of takes the polish off the overall effectiveness of the role.
>
> **Interviewer**: Did you feel you had enough time to do your work properly?
> **SBN**: No.
> **Interviewer**: What did you feel was compromised as a result?
> **SBN**: My self-satisfaction, my ability to leave work and relax because I know I've done all the things I needed to do.

The ongoing manageability of the SBN's caseload is affected by the proportion of time devoted to clinical and non-clinical duties. Some of the time pressure was attributed to the demands of the project (especially regarding documentation) rather than to the clinical pathway. Naturally these demands will cease at the conclusion of this project.

In addition to the clinical skills identified above, time management skills are essential in order for SBNs to maintain a manageable workload without burning out.

Case diversity

The personal impact of the SBN role may also be influenced by the exclusive focus on women with breast cancer. In their telephone interviews and focus group discussions some SBNs reported that they found this level of specialisation difficult, compared with their previous experience of a mixed caseload which included women with benign breast disease. Working only with women with breast cancer was perceived as more exhausting.

> **SBN**: I've found it very frustrating because a lot of the components of my job that I normally do I had to leave off during the time of the project … [O]ur breast clinic has a lot of non-breast cancer people through here and I normally have contact with those. And so I really had to put off seeing those people … [I]n the past I had a bit more balance in my working life.

Despite these issues, some SBNs experienced increased job satisfaction in their new role. As evidenced below, this was linked to a feeling of satisfaction regarding their increased abilities to improve care for women with breast cancer:

> **Interviewer**: Did altering your work practice from your previous role affect your level of job satisfaction?
> **SBN**: Undoubtedly … in a very positive way. Prior to this project I had a management role … there's still core management functions in this role, but it's so clinically based, it's working within the team, and it's much more satisfying … [A]t the end of the day, it's possible to have a much broader influence. I'm able to move through the different departments and different patient care areas … and I'm able to work within the big team there to help to improve services.

When asked directly about the caseload expected within the project (five new patients a week), most SBNs considered the caseload reasonable (although some reported that they did not encounter this caseload). Their feelings of being overworked were thus more often ascribed to project documentation than to caseload. In the rural centre, the expected caseload could not be met due to a lack of patients. However, this SBN filled her time with educational and resource development activities, and reported experiencing a very high workload.

Peer support

When asked whether they felt emotionally burdened by their role as a SBN, respondents were divided, but the majority stated that they did feel burdened at times. Part of this feeling was ascribed to the stress of developing a new role and concerns about doing a good job in it. The move from being part of the nursing team to being more closely connected with the multidisciplinary team involved a change in collegial support patterns and was difficult for some. Despite these changes, the majority of SBNs reported that both their nursing and other treatment team colleagues gave them adequate support. Other interviewees reported that the SBNs were also a good source of support to other treatment team members.

The project's focus on the psychosocial care of women increased the SBNs' feelings of emotional stress. In most cases, however, the SBNs felt that they had adequate skills to deal with this stress:

> **SBN**: [G]enerally you deal with people with breast cancer, but sometimes there's just a person who upsets you for some reason, whether you're the same age, or they've got kids the same age as yours, or for some reason you connect with those differently.
>
> **SBN**: I always experience things that are very, very sad, but at the end of the day I feel I am able to turn off and it doesn't distress me getting to know the real issues that are going on for women … [Y]ou can't avoid finding out about their unhappy relationship, their child that they lost … the turmoil their son's going through at the moment, or the relationship they had with their parent, or [the] great distress or isolation they feel. So people's distress is there, and I'm very aware that I experience a lot of distress every day. But I guess I'm able to distance myself from that distress so it doesn't distress me.

Opportunities to access peer support in order to discuss difficult cases were highly valued by SBNs. However, the quality and quantity of such access varied across each centre. Working with another SBN provided the most accessible opportunities, with one SBN reporting that she is able to talk "almost on a daily basis" with her SBN colleague. Others reporting talking with other nursing colleagues and team members, including social workers, breast physicians and psychologists. In one centre, SBNs attended a regular state meeting of breast nurses and found this a useful forum for airing concerns. One SBN reported having only limited opportunities for peer or other professional support – significantly, this was in a centre which did not have a multidisciplinary team and in which the role encountered greater opposition.

Psychological supervision

Project data indicate that the SBNs' impact on psychological morbidity, directly and through referral, was not as effective as that observed in randomised control trials. As discussed in Chapter 8, additional training and psychological supervision would assist greatly. SBNs are not mental health nurses or psychologists and thus cannot be expected to work at a specialist mental health level.

The opportunity for ongoing case review with a mental health professional could also ensure that SBNs consolidate their psychological skills and thus identify high-risk or high-need women more effectively. This must be seen as a separate issue from peer support and debriefing, and as an important part of the multidisciplinary care of women. Better psychological training and psychological supervision will improve SBNs' confidence to implement the clinical pathway and will also reduce the emotional impact that SBNs experience. As role effectiveness improves, job satisfaction may also increase.

Summary and conclusions

The evidence-based SBN model of care promises to make a significant change to the impact of a breast cancer diagnosis, and the demonstration project has provided valuable data on factors that will influence the feasibility of the approach. These include the need for diverse and advanced clinical and psychosocial skills. Additionally, SBNs require time management skills and strategies to minimise the burnout risks of the position. Access to adequate peer support and professional psychological supervision is essential to the sustainability of the position.

Achieving a workable caseload is ultimately a key determinant of the role. There are multiple factors influencing caseload, but on the basis of the demonstration project a sustainable steady state caseload is in the range of 36-48 women. Changes to the number of consultations, the length of intervention, or the number of competing tasks may vary across sites, and would have a flow-on effect on this caseload which would need to be adjusted accordingly.

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Appendix 1

Summary of the evidence on which the SBN model of care is based

	Intervention and evidence of benefits	Rating of evidence*	Authors
General information	Provide information about treatment goals and options: *reduces psychological morbidity; increases understanding of breast cancer, recall of information and perceptions of support for women with breast cancer*	II	Clacey *et al.* (1995); Maguire et al. (1983); Maguire *et al.* (1980)
	Discuss practical issues: *it benefits women to be provided with information about: the cost of diagnosis and treatment; the cost, availability and types of prostheses; breast reconstruction; travel and accommodation*	IVa	Butler *et al.* (1998); Davis et al. (1997a,b); Burcham (1997)
	Discuss the woman's religious, spiritual and cultural needs: *as a woman's physical health deteriorates, spiritual issues gain importance as determinants of quality of life; NESB women may require special services*	IVa; IVb	Gotay (1985); Temple-Smith *et al.* (1995); Carrick *et al.* (1996)
Specific information	Discuss prognostic issues: *women prefer prognostic issues to be discussed on the first visit, including an explanation about when prognosis will be available*	IVa	Lobb *et al.* (1997)
	Provide information about the procedures they are about to undergo: *reduces emotional distress and improves psychological and physical recovery*	I	Hathaway D (1986); Johnston *et al.* (1993)
General support	Screen for psychological risk factors: *may facilitate early referral for intervention*	II	Wilkinson *et al.* (1988); Maguire et al, (1983)
	Discuss family and support networks: *women with good support have better emotional adjustment and lower psychological distress*	III, IVa	Mor *et al.* (1994); Roberts *et al.* (1994); Neuling et al. (1988); Ell *et al.* (1989)
	Offer appropriate counselling: *improves the wellbeing of women with breast cancer*	I	Devine & Westlake (1995)

**see following page for a description of rating of evidence*

Rating of evidence

The evidence rating system is based on recommendations for intervention studies by the NHMRC's Standing Committee on Quality of Care and Health Outcomes (QCHOC,1995), and has been adapted from the system developed by the US Preventive Services Task Force. The system is as follows:

Level I - Evidence is obtained from a systematic review of all relevant randomised control trials, usually found in meta-analyses.

Level II - Evidence is obtained from at least one properly designed, randomised control trial.

Level III - Evidence is obtained from well-designed controlled trials without randomisation; or from well-designed cohort or case-control analytic studies, preferably from more than one centre of research; or from multiple time series, with or without the intervention.

Level IVa - Evidence is obtained from descriptive studies of provider practices, patient behaviours, knowledge, attitudes or a systematic review of the descriptive studies.

Level IVb - Represents the opinions of respected authorities based on clinical experience or reports of expert committees.

Level I represents the gold standard of evidence. However, this does not mean that treatments based on other levels of evidence cannot be used in appropriate circumstances. Research in this area is characterised by a varying degree of quality in the design of studies. For some issues, such as prevalence studies to identify needs, Level IVa evidence is the most appropriate.

Appendix 2

Collaborating Centre and site codes

Collaborating Centre	Code
Royal Perth Hospital	A
Royal Adelaide Hospital	B
Dubbo Base Hospital	C
Inner and Eastern Health Care Network	D
Alfred Hospital	D1
Peter MacCallum Cancer Institute	D2
Maroondah Hospital	D3
Private Breast Nurse	D4

Appendix 3

SBN qualifications and experience

	Qualifications	Clinical experience	Award level
SBN 1	Registered general nurse: BN; Graduate diploma (health counselling); midwifery certificate; maternal & child welfare certificate; support group leader training	5 years general and midwifery 4 years – surgical oncology 4 years – breast care nurse	CNC (Level 5)
SBN 2	Registered general nurse: certificate; Diploma (professional practice management)	5 years – practice nurse for consultant surgeon (specialty interest – oncology)	CNC
SBN 3	Registered general nurse: certificate; Graduate diploma advanced nursing (management); cancer nursing certificate; distance learning package (breast cancer); crisis line counselling course	8 years – medical oncology	CNC
SBN 4	Registered general nurse: BN (Applied Nursing); post-graduate in community health nursing; distance learning package (breast cancer)	6 years – surgical, medical & radiation oncology	CNC – Grade 4B
SBN 5	Registered general nurse: BSc; Graduate diploma advanced nursing (education); cancer Nursing certificate; distance learning package (breast cancer)	5 years – medical & radiation oncology 3 years – breast care nurse	NUM – Grade 4
SBN 6	Registered general nurse: Diploma in Nursing; BN (in progress); oncology nursing certificate; grief counselling certificate	1 year – oncology 5 years – chemotherapy nurse 5 years – Clinical nurse manager 2 years – Breast nurse counsellor	Level 2 Level 3
SBN 7	Registered general nurse: graduate diploma (oncology/ palliative care) (in progress); distance learning package (breast cancer); hospital-based courses in oncology nursing, palliative care and bereavement counselling	1 year – breast care nurse 5 years – breast cancer support nurse 1 year – oncology	Grade 4A Grade 6

Appendix 4

PATIENT INFORMATION SHEET

.... Hospital &
NHMRC National Breast Cancer Centre
Specialist Breast Nurse Demonstration Project
Information sheet for participants

We know that women diagnosed with breast cancer require information and supportive care. In the United Kingdom, these needs are cared for by a trained specialist breast nurse. These nurses see women at the time of diagnosis and during the course of treatment to provide information and to coordinate supportive care. Little is known about how effective a similar role for nurses would be in improving care for women in Australia.

.... Hospital in collaboration with the NHMRC National Breast Cancer Centre is conducting a project to explore how a specialist breast nurse is able to better meet the support and information needs of women with breast cancer. We are interested in finding out what women think about having a specialist breast nurse help coordinate all of their care.

If you agree to participate, your care will be coordinated by the same breast nurse throughout all of your treatment. The breast nurse will also be available to:

provide you and your family with information, resources, and support according to your own level of need throughout your treatment

organise referrals to other services if necessary

help you with any information or support once you have been discharged from hospital

The nurse will arrange to see you during the course of treatment and later for follow up. She will also provide you with a telephone number should you wish to contact her at any other time during and after your treatment.

You will also be asked to complete two brief questionnaires at 2 and 6 months after diagnosis. The questions will give you the opportunity to describe your level of satisfaction with the information and support provided by the breast nurse and the feelings you were experiencing.

Also, at some time between 6 to 12 months post diagnosis, a trained interviewer will phone you to ask some additional questions. The call will take about 30 minutes. You will be asked about the treatment you had, side effects you may have experienced, and the information and support you received. All information will be strictly confidential. Members of your treatment team will not be told your individual responses. The overall results of the study may be published in a medical journal. No woman’s name will be published.

Your participation in this project is completely voluntary. If you decide not to take part in this study, or withdraw from the study at a later time, your treatment and relationship with .... Hospital will not be affected.

If you require any more information about this study, do not hesitate to contact the breast nurse, ... (Ph ...…....), Dr .... (Ph ....) or Barbara Liebert at the NHMRC National Breast Cancer Centre (Ph 02 9334 1976) for a confidential discussion.

PATIENT CONSENT FORM

Care of women by a breast nurse after diagnosis of breast cancer

This consent form is to be read in conjunction with the patient information sheet for the study.

NAME OF PARTICIPANT:________________________________
ADDRESS:_______________________________________
________________________________ POSTCODE: ______
TELEPHONE: ________________ (H) ___________________(W)

AGREEMENT:

I understand that participation in this project is entirely voluntary and that if I decide to withdraw at any time this will not affect the care I receive from …….. Hospital.

I have been informed that the personal information which I provide will be confidential to the researchers, and that the results of the study will be published in a form that will not allow individuals to be identified.

I understand that my contact details will be given to the breast nurse and that she will be contacting me at regular intervals. I also understand that participation in the study involves the completion of two questionnaires at two and six months after diagnosis, and completing a survey by phone six to twelve months after diagnosis.

I consent to participate in the above study, details of which have been fully explained to me by the researchers involved.

SIGNED: ________________________ DATE: ___________

WITNESS (signature): ______________ DATE: ___________

Appendix 5

Recruitment rates of intervention group, by site

Dubbo	**Dubbo**	**Adelaide**	**Perth**	**Alfred**	**Peter Mac**	**Morundah**	**Private nurse**	
Total number of patients seen by breast nurse	77	221	223	217	294	240	60	
Total number of women with breast cancer seen by breast nurse	75	152	152	91	226	157	38	
Total number of eligible women	28	60	47	11	50	54	22	
Total number of women refusing to participate or not recruited by BN	1	12	2	4	1	7	4	
Total number of women recruited	**27**	**47**	**44**	**9**	**48**	**47**	**18**	**240**
Percentage of eligible women recruited	96%	78%	94%	82%	96%	87%	82%	

Appendix 6

Reason for exclusion of ineligible women, by site

	Dubbo		**Adelaide**		**Perth**		**Alfred**		**Peter Mac**		**Morundah**		**Private nurse**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
New diagnosis of breast cancer but failed to meet all inclusion criteria	9	18	22	13	30	17	13	6	32	13	19	10	1	3
Already receiving or completed treatment for breast cancer	29	59	40	25	61	35	55	27	105	43	55	30	13	34
Diagnosed with systemic breast cancer	6	12	7	4	9	5	9	4	26	11	13	7	0	0
Diagnosed with benign breast disease	2	4	69	43	71	40	14	7	50	20	83	45	22	58
Diagnosed with cancer other than breast cancer	0	0	0	0	0	0	112	54	18	7	0	0	0	0
Previous history of breast cancer – consultation re reconstruction/ prosthesis	3	6	25	16	6	3	3	1	14	6	16	9	2	5
Total	**49**		**163**		**177**		**206**		**245**		**186**		**38**	

Appendix 7

Socio-demographic profile of women in the intervention group (n=240)

Demographic characteristic		**n (%)**
Age		
	Range	25-90 years
	Mean	56 years
	Median	55 years
	SD	12.7 years
Age group		
	18-29	3 (1.3)
	30-39	17 (7.1)
	40-49	53 (22.2)
	50-59	74 (31.0)
	60-69	49 (20.5)
	70-79	35 (14.6)
	80+	8 (3.3)
Marital status		
	Never married	23 (9.7)
	Married/de facto	153 (64.3)
	Separated/divorced	28 (11.7)
	Widowed	34 (14.3)
Education		
	Below Secondary	94 (39.2)
	School Certificate	37 (17.1)
	Higher School Certificate	37 (17.1)
	Technical College	17 (7.8)
	University/CAE	32 (14.7)
	Other	----
Place of residence		
	Rural/ remote	21 (12.6)
	Country town/ centre	43 (25.7)
	Major city	103 (61.7)
Average length of stay at hospital		4.97 days
Children		
	None	38 (15.8)
	Younger than 21 years	81 (33.8)
	Older than 21 years	148 (61.7)

Appendix 8

Frequency and time spent by SBNs on non-daily basis activities

Activities	Days	Frequency	Mean (mins)	Mode (mins)
Clinical activities				
Patient meeting	73	2/week	46	41-60
Patient contact	80	2/week	19	1-20
Patient groups	15	1-2/month	104	>60
Non-clinical activities				
Administration	155	4/week	57	41-60
Staff meetings	110	3/week	36	21-40
Staff contact	110	3/week	30	1-20
Meetings	31	1/week	58	41-60
Debriefing	55	1-2/week	20	1-20
Activities related to project	148	4/week	63	>60
Activities related to other projects	46	1/week	42	1-20
Teaching	61	1-2/week	67	>60
Professional development	55	1-2/week	49	21-40
Travel	47	1/week	40	1-20
Other	39	1/week	48	21-40

Total number of days: 195 (39 weeks for 5 working days/week)

Appendix 9

SBN's time spent on activities, per day

Clinical activities	**Hours: Mins**	**%**
Direct	2:35	34
Face-to-face consultations	1:31	20
Telephone consultations	:20	4
Support patients during doctors' consultations	:16	4
Activities related to non-breast cancer patients	:15	3
Clinical duties (eg wound dressing)	:13	3
Indirect	:55	12
Documentation	:31	7
Verbal handover to other health professionals	:13	3
Referral of patients to various practitioners	:11	2
Other	:33	8
Multi-disciplinary meetings	:17	4
Leading support groups	:8	2
Informal patient contact	:8	2
Total clinical activities	4:03	54

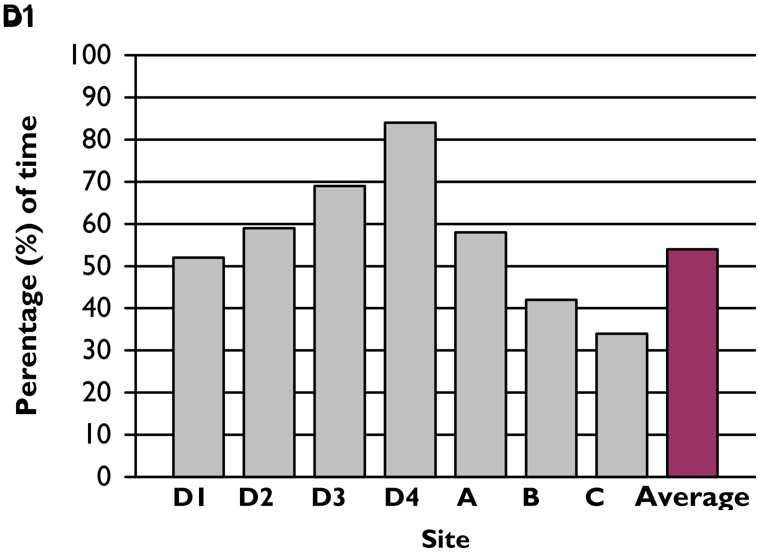
Non-clinical activities	**Hours:Mins**	**%**
Project	:58	13
This SBN project	:48	11
Other Collaborating Centre projects	:10	2
Meetings	:51	11
Staff meetings	:20	4
Staff contact	:17	4
General meetings	:9	2
Debriefing of SBNs	:5	1
Administration	:45	10
Education	:35	8
Teaching students	:21	5
Professional development	:14	3
Other	:18	4
Travelling (eg home visits)	:9	2
Other	:9	2
Total non-clinical activities	3:27	46

Total number of days: 195

Total hours worked per day: 7.5 hours (450 minutes)

Appendix 10

Proportion of time spent by SBNs on clinical activities for individual sites



Appendices 11 and 12

Appendix 11

Proportion of different types of women seen by SBNs for all sites

Patient type	**Frequency***	**(%)**
Non-breast cancer patients	278	22
Breast cancer patients in the study	510	40
Breast cancer patients not in the study	373	29
Patients of unknown type	117	9

**includes multiple visits by patients*

Appendix 12

Proportion of different types of women seen by SBNs, by site

Patient type	**Site**						
	A	**B**	**C**	**D1**	**D2**	**D3**	**D4**
	%	**%**	**%**	**%**	**%**	**%**	**%**
Non-breast cancer (0)	15	23	5	45	18	20	44
Breast cancer in study (1)	50	53	45	18	43	59	35
Breast cancer non-study (2)	35	24	50	37	39	21	21
Total breast cancer (1+2)	85	77	95	55	82	80	56

Appendix 13

Proportion of time spent by SBNs on clinical activities with different patient types, by site

Patient type	Site A %	 B %	 C %	 D1 %	 D2 %	 D3 %	 D4 %
Non-breast cancer (0)	11	15	3	40	13	10	38
Breast cancer in study (1)	59	63	50	25	57	75	37
Breast cancer non-study (2)	30	22	47	35	30	15	25
Total breast cancer (1+2)	89	85	97	60	87	90	62

Appendix 14

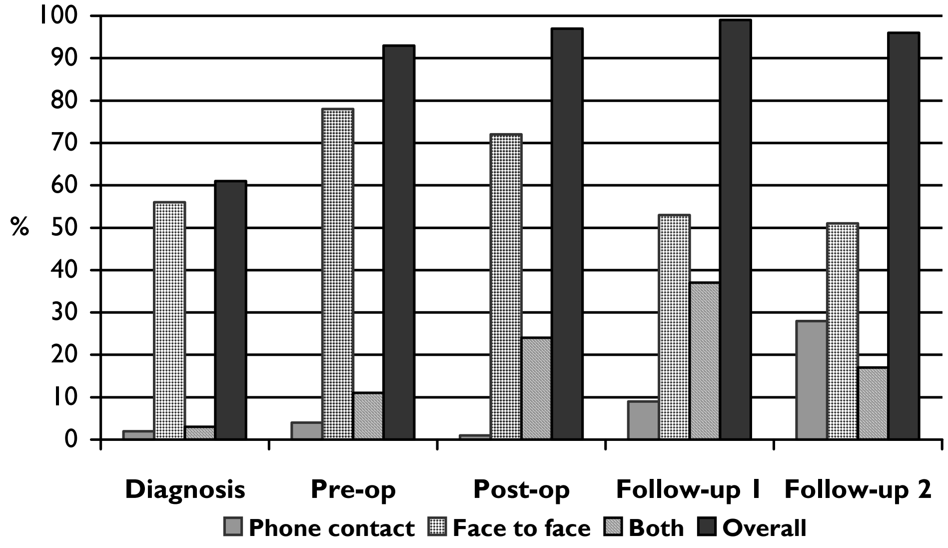
SBN caseload trends over time

	Month					
Characteristic	**March**	**April**	**May**	**June**	**July**	**August**
Number of patients seen by SBNs/week	25	27	30	32	36	35
Number of hours worked by SBNs/week	32	35	33	37	38	38
Time spent on direct & indirect clinical activities (mins/breast cancer patient)	39	37	33	36	39	34
Time spent on direct & indirect clinical activities (mins/non-breast cancer patient)	28	24	19	24	22	26

Appendices 15 and 16

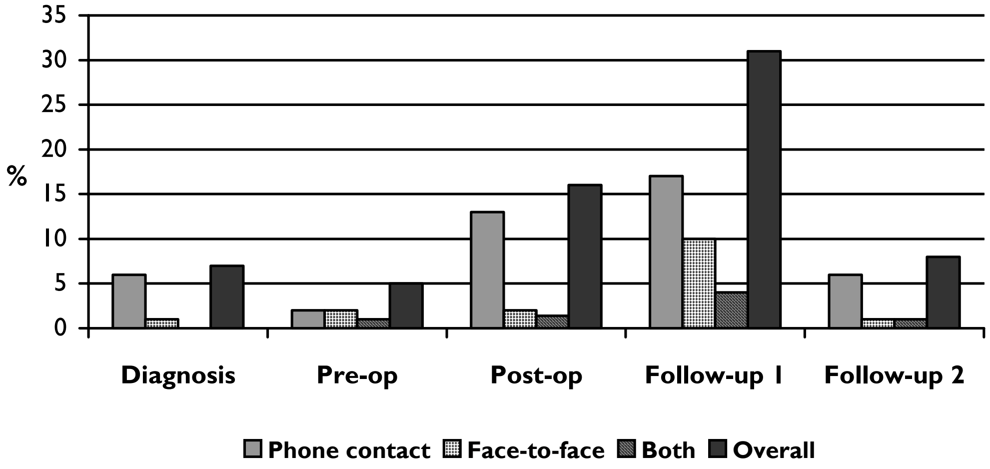
Appendix 15

Proportion of women receiving each nurse-initiated consultation at each treatment phase



Appendix 16

Proportion of women initiating consultations at each treatment phase



Appendix 17

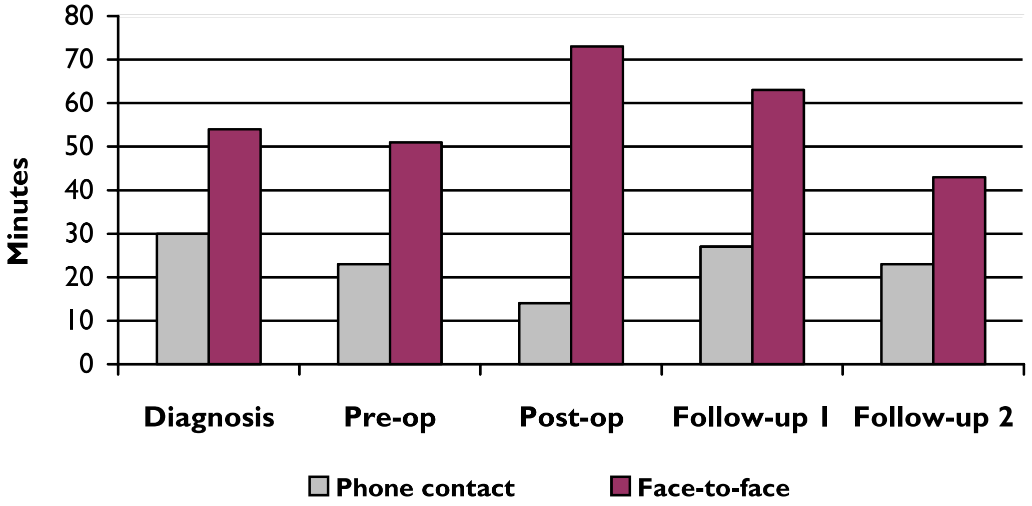
Frequency of patient-initiated consultations, by treatment phase

	Frequency							
Phase	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Diagnosis	16	1	0	0	0	0	0	0
Pre-operative	7	1	1	0	0	1	0	1
Post-operative	29	7	2	1	0	0	0	0
Follow-up 1	40	24	7	2	1	0	0	0
Follow-up 2	13	4	2	1	0	0	0	0
Total number	105	37	12	4	1	1	0	1
Percentage	65%	23%	8%	2.5%	0.5%	0.5%	0%	0.5%

Appendices 18 and 19

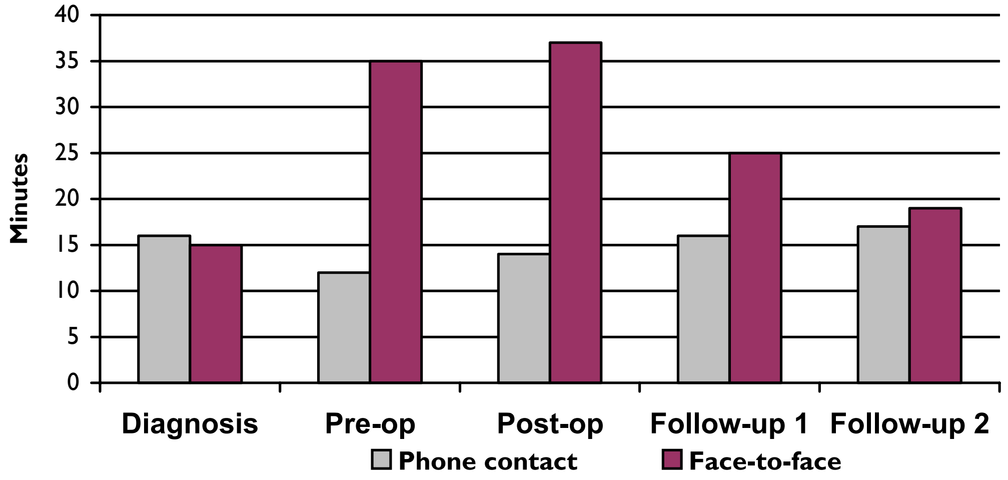
Appendix 18

Average length of SBN-initiated consultations, by treatment phase



Appendix 19

Average length of patient-initiated consultations, by treatment phase



Appendix 20

Frequency distribution of length of women's relationships with SBNs

Length	Frequency	Percentage	Cumulative percentage
<8 weeks	32	14%	14%
8–12 weeks	129	54%	68%
13–16 weeks	54	23%	91%
>16 weeks	22	9%	100%
Total	237	100%	

Appendix 21

Proportion of SBN-identified needs of women, by treatment phase

Needs	Treatment phase				
	Diagnosis %	Pre-op %	Post-op %	Follow-up 1 %	Follow-up 2 %
Cancer					
Experience of having cancer	7	3	4	1	3
Understanding a diagnosis of cancer	23	21	14	10	12
Prognosis	8	16	35	30	5
Experience of cancer in others	4	2	2	4	0
Health					
Physical symptoms	2	2	14	31	21
General health/background	6	8	10	10	13
Treatment					
Surgery	30	53	19	6	3
Radiotherapy	6	6	15	16	10
Adjuvant therapy	4	4	17	44	14
Breast reconstruction	4	5	5	6	2
General	18	30	45	33	18
Problems after treatment	2	3	15	34	22
Psychological needs					
Psychological symptoms	25	51	52	49	40
Psychosexual needs	2	6	6	9	10
Family concerns/relationship	17	17	19	16	18
Social and practical needs					
Occupation	5	4	4	7	3
Finance	5	8	6	10	5
Experience/feelings about health care	5	4	4	8	7
Practical problems	9	9	18	16	8
Support	10	14	11	12	20
Other needs	3	3	2	6	3

Total number of patients: 237

Appendix 22

Proportion of women receiving different interventions, by treatment phase

	Treatment phase				
Intervention	**Diagnosis %**	**Pre-op %**	**Post-op %**	**Follow-up 1 %**	**Follow-up 2 %**
Information	57	79	84	86	59
Counselling	33	66	73	73	65
Treatment	0	1	12	19	5
Liaison/referral	18	32	42	49	33

Appendix 23

Number of resources given to women during SBN-initiated consultations, by treatment phase

Treatment phase	Number of resources 0 %	 1-5 %	 6-10 %	 >10 %
Diagnosis (n=145)	17	37	44	2
Pre-operative (n=215)	41	39	19.5	0.5
Post-operative (n=226)	39	33	14	14
Follow-up 1 (n=232)	61	38	1	0
Follow-up 2 (n=221)	92	8	0	0

Appendix 24

Proportion of women referred to various practitioners, by treatment phase

	Treatment phase				
Practitioner	**Diagnosis %**	**Pre-op %**	**Post-op %**	**Follow-up 1 %**	**Follow-up 2 %**
Psychologist	0.4	2.5	0.8	3.4	3
Psychiatrist	0.4	0.4	0.8	0.4	0.4
Social worker	6.3	16	11.8	8.9	2.1
Welfare worker	0	0.4	0	0	0
Physiotherapist	2.5	17.7	38	7.2	1.3
Occupational therapist	1.3	6.3	0.4	1.7	0.4
Diversional therapist	0	0	0	0	0
Radiotherapy	0	0.4	1.7	3.4	0.8
Chemotherapy	0	0	0.4	4.2	0.8
Community nurse	0.8	0.4	27	5.9	0.4
General practitioner	0	0.4	12.7	0.4	0.4
Breast cancer support group	3.8	11.4	23.6	3.0	0.8

Total number of patients: 237

Appendix 25

Occupations of interviewees, by site

		Site							
Occupation		**A**	**B**	**C**	**D1**	**D2**	**D3**	**D4**	**Total**
Medical	Surgeon	2	3	2	1	1	1		10
	Oncologists	1	2	2	2	2	1	2	12
Nursing	Nursing unit manager			1	1	1	1	2	6
	Ward nurse	1	1	1					3
	Outpatient nurse		1					1	2
	Discharge nurse	1		1					2
SBN	Breast nurse	1	1	1	1	1	1	1	7
Allied health	Physiotherapist	1	1	1			1		4
	Psychosocial*	1	2	1	1	1	1		7
BCSS	Breast Cancer Support Service	1	1	1					3
Community health professionals	Community nurse		1						1
	General practitioner			1				1	2
Other	Other				1				1
Total		9	13	12	7	6	6	7	60

**social worker, psychologist, counsellor*

Appendix 26

SBN questionnaire response rate, by site

	Site							
	A	**B**	**C**	**D1**	**D2**	**D3**	**D4**	**Total**
2-month questionnaire								
Completed (n)	36	43	24	9	42	45	18	219
Response rate	82%	91%	85%	100%	88%	96%	100%	92%
6-month questionnaire								
Completed (n)	37	42	23	9	40	40	18	209
Response rate	84%	89%	85%	100%	83%	85%	100%	87%

Appendix 27

Women's perceptions of the SBN's coordination of care and its benefits

Characteristic	Perception Received as much help as needed n (%)	Wanted more support n (%)	Wanted less support n (%)	Did not need help n (%)
Understanding who treatment team was	162 (88)	5 (3)	0 (0)	17 (9)
Making sure doctors knew what was happening/needs	156 (80)	8 (4)	1 (0.5)	30 (5)
Introduction to treatment team	143 (75)	9 (5)	0 (0)	39 (20)

	Great benefit n (%)	Some benefit n (%)	No benefit n (%)
Continuity of care from SBN	170 (88)	17 (9)	6 (3)

Appendix 28

Women's perceptions of the SBN's offering of referrals

Characteristic	Perception Yes n (%)	 No n (%)	 Don't know n (%)	N/A n*
Did breast nurse suggest/offer chance to talk to the following?				
Social/welfare worker	100 (67)	46 (31)	3 (2)	46
Counsellor/psychologist/ psychiatrist	66 (52)	53 (42)	7 (3)	56
Breast Cancer Support Service	152 (84)	24 (13)	5 (3)	12
Cancer Information Service	126 (76)	29 (17.5)	11 (6)	18
Physiotherapist	89 (61)	51 (35)	6 (4)	39
Occupational/diversional therapist	31 (30)	63 (61)	10 (10)	79
Radiotherapy/ chemotherapy nurse	72 (59)	46 (38)	4 (3)	56
Your GP or a community nurse	90 (60)	54 (36)	5 (3)	39
Someone of your culture/religion	25 (37)	38 (57)	4 (6)	113

**"Not applicable" responses are not included in the calculation of percentages.*

Appendix 29

Women's perceptions of the SBN's provision of information

Information content	Perception			
	Right amount n (%)	Wanted more n (%)	Wanted less n (%)	Don't know n (%)
Diagnosis	173 (92.5)	12 (6)	1 (0.5)	1 (0.5)
Prognosis	151 (91)	13 (8)	0 (0)	2 (1)
Treatment choices and goals	152 (90)	14 (8)	0 (0)	3 (2)
Practical support	52 (84)	6 (10)	1 (2)	3 (5)
Surgery, what it is/what to expect	171 (90.5)	13 (7)	0 (0)	5 (3)
Results of surgery	161 (87)	18 (10)	0 (0)	6 (3)
Radiotherapy, what it is/what to expect	105 (86)	15 (12)	0 (0)	2 (2)
Chemotherapy, what it is/what to expect	71 (90)	5 (6)	0 (0)	3 (4)
Breast reconstruction	59 (83)	7 (10)	1 (1)	4 (6)
Breast prostheses	89 (90)	5 (5)	1 (1)	4 (4)
Clinical trials	82 (81)	7 (7)	1 (1)	11 (11)
Caring for wound at home	155 (90)	15 (9)	0 (0)	3 (2)
Discharge and treatment plan	159 (90)	18 (10)	0 (0)	1 (1)
Breast Cancer Support Service	105 (90)	4 (3)	0 (0)	9 (8)
Cancer Information Service	118 (87)	4 (3)	0 (0)	13 (10)
Support groups	107 (86)	6 (5)	0 (0)	11 (10)

Appendix 30

Women's perceptions of the SBN's provision of resources

Resource	Perception Yes n (%)	 No n (%)	 Don't know n (%)	N/A n*
Printed resources	200 (100)	0	0	1
Breast cancer audio/video tapes	100 (60)	58 (35)	9 (5)	26
Breast cancer hospital fact sheet	161 (82)	22 (10)	13 (7)	4
Written information re own diagnosis	78 (45)	84 (48)	13 (7)	13
Tape of any consultations	129 (73)	45 (25)	3 (2)	19
Specific resources for rural women	36 (58)	18 (29)	8 (13)	116
Specific resources for partners	101 (74)	27 (20)	8 (6)	56
Specific resources for children	60 (58)	36 (35)	8 (7)	82

**"Not applicable" responses are not included in the calculation of percentages.*

Appendix 31

Women's perceptions of the SBN's provision of emotional support

	Perception			
Characteristic	**Yes, lot more**	**Yes, little more**	**No, right amount**	**No, too much**
	n	**n**	**n**	**n**
Felt you needed more emotional support from breast nurse	5 (2.5%)	21 (10%)	172 (86%)	3 (1.5%)

	Yes	**No**	**N/A***
	n	**n**	**n**
Felt you required more emotional support from professional counsellor	30 (18%)	137 (82%)	37

	Yes	**No**	**Don't know**	**N/A***
				n
Did breast nurse offer to organise more professional counselling	65 (59%)	35 (31%)	11 (10%)	88

**"Not applicable" responses are not included in the calculation of percentages.*

Appendices 32 and 33

Appendix 32

Women's perceptions of the SBN's communication skills

Skill	Perception Strongly agree n (%)	Agree n (%)	Disagree n (%)	Strongly disagree n (%)	N/A n*
Breast nurse was a good listener	152 (75)	49 (23)	1 (0.5)	0 (0)	0
Could share feelings with breast nurse*	59 (33)	76 (42)	10 (5.5)	36 (20)	9
Breast nurse good at explaining	154 (77)	42 (21)	4 (2)	0 (0)	3
Breast nurse knew when to/not to talk	130 (65)	58 (29)	5 (2.5)	3 (1.5)	4
Breast nurse communicated with doctors	80 (50)	82 (46)	9 (5)	7 (4)	16
Breast nurse communicated needs to GP & other health workers	72 (49)	53 (36)	13 (9)	8 (5.5)	54

"Not applicable" responses are not included in the calculation of percentages.

Appendix 33

Women's perceptions of the SBN's provision of support for family and friends

Characteristic	Perception Much help as needed n (%)	Wanted more support n (%)	Wanted less support n (%)	Did not need help n (%)
Opportunity to ask questions and talk about feelings	149 (71)	8 (4)	1 (0.5)	48 (24)
Information about illness	153 (77)	6 (3)	1 (0.5)	38 (18)

Appendix 34

Women's perceptions of the SBN's provision of information about practical support

Information content	Perception Much help as needed	 Wanted more support	 Wanted less support	 Did not need help
	n (%)	n (%)	n (%)	n (%)
Organising travel/accommodation	43 (24)	4 (2)	0 (0)	134 (74)
Getting a prosthesis	84 (46)	2 (1)	0 (0)	97 (53)
Understanding cost of treatment	68 (37)	6 (3)	0 (0)	111 (60)
Choosing the best hospital for me	64 (33)	7 (4)	1 (0.5)	120 (62.5)
Understanding length of hospital stay	166 (83)	6 (3)	0 (0)	29 (14)
Understanding what would happen when discharged	168 (83)	17 (8)	0 (0)	18 (9)
Organising assistance with chores whilst recovering at home	42 (22)	13 (7)	0 (0)	138 (71)

Appendix 35

Women's perceptions of the SBN's provision of support for religious and/or cultural needs

	Perception			
Characteristic	**Yes** **n (%)**	**No** **n (%)**	**Don't know** **n (%)**	**N/A** **n***
Opportunity to talk about spiritual aspects of having breast cancer	42 (37)	65 (58)	6 (5)	76
Information suited to own language or culture	30 (64)	14 (30)	3 (6)	138
Chance to talk to someone from own language/culture	17 (59)	11 (38)	1 (3)	158
Chance to talk to someone with similar religious/ spiritual beliefs	18 (33)	34 (63)	2 (4)	131

"Not applicable" responses are not included in the calculation of percentages.

Appendix 36

Women's satisfaction with timing of SBN consultations

Characteristic	Perception Strongly agree n (%)	Agree n (%)	Disagree n (%)	Strongly disagree n (%)
Diagnosis:				
Appropriate time to see SBN (n=156)	129 (82)	26 (17)	1 (1)	0 (0)
SBN made treatment options clearer (n=168)	90 (54)	46 (27)	16 (9.5)	16 (9.5)
SBN assisted to make decision about treatment (n=157)	96 (61)	48 (31)	9 (6)	4 (2)
Pre-operatively:				
Appropriate time to see SBN (n=173)	137 (79)	35 (20)	1 (1)	0 (0)
Speaking to SBN helpful at this stage (n=197)	157 (79.5)	39 (20)	1 (0.5)	0 (0)
Post-operatively:				
Appropriate time to see SBN (n=178)	136 (76)	41 (23)	1 (1)	0 (0)
Speaking to SBN helpful at this stage (n=203)	157 (77.5)	45 (22)	1 (0.5)	0 (0)

Follow-up visits:	Well-timed n (%)	Prefer some change n (%)	Badly-timed n (%)
Timing of SBN consultations	157 (89)	18 (10)	2 (1)

Appendix 37

Women's satisfaction with the structure of the SBN model, at different treatment phases

Characteristic	Perception Right amount n (%)	 Too many n (%)	 Too few n (%)
Diagnosis, pre-op & post-op			
Number of consultations	199 (93%)	2 (1%)	12 (6%)
	Right length	Too long	Too short
Length of consultations	205 (97%)	2 (1%)	5 (2%)
	Satisfied	Not satisfied	
Availability/ accessibility of SBN	133 (94%)	9 (6%)	
	Great benefit	Some benefit	No benefit
Continuity of care from SBN	170 (88%)	17 (9%)	6 (3%)

Follow-up visits			
	Right amount	Too many	Too few
Number of consultations	158 (86%)	1 (0.5%)	25 (13.5%)
	Right length	Too long	Too short
Length of consultations	172 (94.5)	1 (0.5%)	9 (5%)
	Satisfied	Not satisfied	
Availability/ accessibility of SBN	120 (91.5%)	11 (8.4%)	
	Helpful	Not helpful	
Set schedule of visits	143 (83%)	29 (17%)	

Appendices 38 and 39

Appendix 38

Response rates of intervention group for telephone interview, by Collaborating Centre

	Centre				
Characteristic	**A**	**B**	**C**	**D**	**Total**
Total number of women recruited	44	47	27	122	240
Revoked consent/not able to be contacted	3	2	0	7	12*
Sent to external agency for interview	41	45	27	115	228
Completed interview	35	37	20	75	167
Response rate of those recruited	80%	79%	74%	61%	70%
Response rate of those sent to external agency	85%	82%	74%	65%	73%

**Five women revoked consent and the other seven were not able to be contacted.*

Appendix 39

Distribution of women across intervention and retrospective control groups, by Collaborating Centre

	Distribution	
Centre	**SBN group**	**Retrospective control**
	n (%)	**n (%)**
A	35 (21)	39 (29)
B	7 (22)	61 (46)
C	20 (12)	18 (14)
D	75 (45)	15 (11)
Total	167 (100)	133 (100)

Appendix 40

Retrospective control group: reasons for exclusion of ineligible women, by site

	Site			
Reason for exclusion*	**A**	**B**	**C**	**D2[a, b]**
Not diagnosed with breast cancer	1	0	0	
Patient had systemic disease	1	4	1	
Too ill	4	0	0	
Too emotionally disturbed	2	3	3	
Poor English	7	3	0	
Deceased	3	6	0	
Other	0	4	0	
National Control Group	8	4	0	
Total number of women excluded	26	24	4	

** 3 women had two reasons for exclusion*

[a] *Site D nominated only centre, D2 for the retrospective control*

[b] *Missing data*

Appendix 41

Socio-demographic profile of participants of the intervention (SBN group) and the two control groups

	Group			
Characteristic	**NS (n=532) n (%)**	**RC* (n=133) n (%)**	**SBN (n=167) n (%)**	**SBN (n=240) n (%)**
Age				
Range (years.)	26-95	36-92	28-91	25-90 years.
Mean (years.)	59.0	59.6	56.8	56 years.
SD (years.)	12.3	12.3	12.7	12.7 years.
Age group				
18-29	2 (0)	---	2 (1)	3 (1.3)
30-39	26 (5)	3 (2)	10 (6)	17 (7.1)
40-49	100 (19)	30 (23)	40 (24)	53 (22.2)
50-59	170 (32)	37 (28)	51 (30)	74 (31.0)
60-69	126 (24)	32 (24)	33 (20)	49 (20.5)
70-79	84 (16)	25 (19)	23 (14)	35 (14.6)
80+	24 (4)	6 (4)	8 (5)	8 (3.3)
Marital status				
Never married	25 (5)	8 (6)	12 (7)	23 (9.7)
Married/ defacto	386 (72)	81 (61)	113 (68)	153 (64.3)
Separated/ divorced	36 (7)	21 (16)	18 (11)	28 (11.7)
Widowed	85 (16)	23 (17)	24 (14)	34 (14.3)
Education				
Below secondary	144 (27)	51 (38)	43 (26)	94 (39.2)
School certificate	128 (24)	30 (23)	45 (27)	37 (17.1)
Higher School Certificate	94 (18)	26 (20)	33 (20)	37 (17.1)
Technical college	37 (7)	10 (7)	11 (7)	17 (7.8)
University/CAE	122 (23)	16 (12)	31 (18)	32 (14.7)
Other	5 (1)	---	4 (2)	---
Place of residence				
Rural/ Remote	49 (9)	16 (12)	21 (12)	21 (12.6)
Country town/Centre	51 (28)	36 (27)	43 (26)	43 (25.7)
Major city	332 (63)	81 (61)	103 (62)	103 (61.7)
Children				
None	71 (13)	16 (12)	21 (13)	4.97
<18 years	98 (18)	26 (20)	---	---
≥18 years	384 (72)	101 (76)	---	38 (15.8)
<21 years	---	---	37 (22)	81 (33.8)
≥21 years	---	---	125 (75)	148 (61.7)

NS = National sample; RC= Retrospective control; SBN = Intervention group.

* *Adjusted for sampling by centre – see statistical note page 60.*

Appendix 42

Test results for comparison of socio-demographic characteristics between intervention (SBN group) and two control groups

	Comparison		
Characteristic	**SBN vs NS**	**SBN vs RC**	**NS vs RC**
Age[a]	0.04	0.06	0.66
Education[b]	0.46	0.05	0.004
Marital status[c]	0.19	0.47	0.005
Place of residence[d]	0.41	0.96	0.62

NS = National sample; RC= Retrospective control; SBN = Intervention group.

[a] *Using student's t test.*

[b] *Using Mantel-Haenszel chi-square trend test with 1 df.*

[c] *Using overall chi-square test with 3 df.*

[d] *Using overall chi-square test with 2 df.*

Appendix 43

Women's perceptions of issues regarding diagnosis and treatment decision-making

Characteristic	Group NS %	 RC* %	 SBN %
The way the diagnosis was told – face-to-face	86	90	82
Style of breaking bad news – honest/open/frank	90	92	87
Involved as wanted in decision-making about treatment	73	75	75
When involved as wanted – who decided†			
doctor	17	11	18
own or family	25	35	22
jointly with doctor	58	54	60
When discussed treatment options, decided about treatment straight away	41	42	41
Allowed as much time as needed to make decision	83	87	86

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60.*

† Percentage of those for whom applicable.

Appendix 44

Women's perceptions of care received (regarding clinical trials)

	Group		
Characteristic	**NS** **%**	**RC**[*] **%**	**SBN %**
Women told about clinical trials	14[a]	26[a,b]	40[b]
[†]Proportion who participated when told	41	37	45
Percentage of total population who participated in clinical trials	6	10[c]	18[c]

NS = National sample; RC= Retrospective control; SBN = Intervention group.

**Adjusted for sampling by centre – see statistical note page 60*

a $\chi^2=5.3$; $p=0.02$

b $\chi^2=8.9$; $p=0.003$

c $\chi^2=8.5$; $p=0.004$

Appendices 45 and 46

Appendix 45

Information resources offered by treatment team members

Characteristic	Group NS %	 RC* %	 SBN %
NBCC booklet, video or audio tape about early breast cancer	66	78	83
Hospital fact sheet	34[a]	44[a,b]	59[b]
Audio tape of their consultation with any member of their treatment team	4[c]	14[c,d]	57[d]

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60*

a $\chi^2 = 4.97; p = 0.03$

b $\chi^2 = 4.24; p = 0.04$,

c $\chi^2 = 20.07; p < 0.001$,

d $\chi^2 = 64.54, p < .0001$

Appendix 46

Women's satisfaction with information received

Characteristic	Group NS %	 RC* %	 SBN %
Woman received right amount of information about treatment and support		85	83
Family had access to information as much as needed[†]	73	72	81
Woman received as much information as needed about:			
Treatment	84	87	91
Surgery	79[a]	83[a]	87
Radiotherapy	81	80	88
Additional treatment	76	82	81
Side effects	74	79	80
Prognosis	82	80	88

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** adjusted for sampling by centre – see statistical note page 60*

[†] *percentage of those for whom applicable*

a $\chi^2 = 6.92\ p < 0.01$

Appendices 47 and 48

Appendix 47

Types of physical treatment received

	Group		
Characteristic	**NS**	**RC***	**SBN**
	%	%	%
Treatment received:			
Mastectomy	32 [a]	47 [a]	35
Mastectomy + Radiotherapy	13 [a]	10 [a]	10
Lumpectomy	7 [a]	4 [a]	6
Lumpectomy + Radiotherapy	32 [a]	35 [a]	44
*Others	8	4	5
Main reason for treatment – best surgery:†			
Mastectomy	63	50	68
Mastectomy + Radiotherapy	100	81	94
Lumpectomy	89	88	90
Lumpectomy + Radiotherapy	83	82	90

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60*

[a] χ^2 =25.4, 3 df; p<0.001

**Not included in calculating χ^2*

† Percentage of those for whom applicable

Appendix 48

Women's length of stay away from home for treatment

	Group		
Characteristic	**NS**	**RC***	**SBN**
Average days away from home	44.3	48.3	48.4
Average length of stay in hospital (days)	5.8 [a]	5.0 [a]	4.9

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60*

a *z=2.38; p<0.05.*

Appendices 49 and 50

Appendix 49

Side effects experienced with different types of treatments

Characteristic	**Group**		
	NS	**RC***	**SBN**
	%	**%**	**%**
Side-effects/complications experienced			
Wound infection	9	14	12
Pain in the upper arm	21	29	16
Swelling in the arm – lymphoedema	17	18	11
Numbness in the armpit	34	34	22
Limited shoulder movement	16	27	10
Menopause symptoms, such as hot flushes	16	20	7
No complications	32	27	35

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60.*

Appendix 50

Breast reconstruction and prosthesis

Characteristic	Group NS %	 RC* %	 SBN %
Breast Reconstruction			
Received as much information as needed	72	62	78
Had or considered having breast reconstruction	8[a]	10[a]	17
Reason for not having breast reconstruction:†			
Did not want to have any more surgery	19	27	19
Did not think it was necessary	60	58	50
Other reasons	21	15	31
Breast prostheses			
Received as much information as needed	82	85	93
Received an external breast prosthesis	33	47	32
Main reason for not having breast prosthesis:†			
Did not feel the need to have one	71	60	59
If received breast prosthesis: †			
Had enough information about prosthesis	70[b]	89[b]	89
Was aware about the availability	66	69	67
Received financial support for prosthesis	78	88	81

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60.*

† Percentage of those for whom applicable.

a $\chi^2 = 3.76; p=0.05$

b $\chi^2 = 8.1; p=0.004$

Appendices 51 and 52

Appendix 51

Women's perceptions of care received (regarding follow-up plan after treatment)

Characteristic	Group NS %	 RC* %	 SBN %
Given follow-up plan after treatment	79	82	76
Received right amount of information	78 [a]	86 [a]	88
If provided, the follow-up plan was†			
Verbal	52 [b]	38 [b]	75
Written	18 [b]	15 [b]	7
Both verbal & written	30 [b]	47 [b]	18

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60.*

† Percentage of those for whom applicable.

a $\chi 2 = 5.4$ $p=0.02$

b $\chi 2 = 38.8$,2 df, $p<0.001$

Appendix 52

Women's satisfaction with care received (regarding practical assistance issues)

Characteristic	Group NS %	 RC* %	 SBN %
Received as much information as needed about:			
Likely cost of treatment	70	72	87
Financial support	56	69	77
Accommodation	71	86	76
Needed practical assistance (travel & accommodation) got it/ did not need any support	95	95	96
If stayed overnight, received or not entitled support for travel & accommodation†	66	71	76

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60.*

† Percentage of those for whom applicable.

Appendices 53 and 54

Appendix 53

Women's satisfaction with care received (regarding Breast Cancer Support Service)

Characteristic	**Group**		
	NS	**RC***	**SBN**
	%	**%**	**%**
Received BCSS booklet	54[a]	65[a]	69
Woman used BCSS volunteer for support	36	40	31
Family used BCSS volunteer for support	5	5	2
Reasons for not using support services:			
Had heard but did not think useful/ received enough support from family[†]	63	72	78

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60.*

[†] *Percentage of those for whom applicable.*

a $\chi^2 = 4.93; p=0.03$

Appendix 54

Women's satisfaction with support received

Characteristic	NS %	Group RC*# %	SBN %
Woman used breast nurse for support	23[a]	61[a,b]	90[b]
Woman's family used breast nurse for support	7[c]	33[c,d]	53[d]
Received as much information about counselling as needed	75	78	86
Received as much information about emotional/practical support as needed	67	66	79
Woman received as much support as needed	83	84	89
Family received as much support as needed†	65	71	76
Overall standard of care – highly satisfactory	83	82	83

NS = National sample; RC= Retrospective control; SBN = Intervention group.

** Adjusted for sampling by centre – see statistical note page 60.*

† Percentage of those for whom applicable.

#Not included in calculating chi-square.

a $\chi^2 = 65.3; p<0.001$

b $\chi^2 = 37.1; p<0.001$

c $\chi^2 = 41.3; p<0.001$

d $\chi^2 = 15.5; p<0.001$

Appendix 55

Frequency of psychosocial risk factors reported in patient logs

	Frequency	
Risk factor	**n**	**%**
Age <50 years	73	30.4
Psychiatric history	33	14.0
Number of children <21 years		
1 child	26	10.9
2 or more	55	23.0
Social Support	27	11.2
Poor relationship with partner	24	10.2
Poor family functioning	29	12.3
Economic difficulties	34	13.4
Ongoing stressors	57	24.1
Cumulative Risk		
No risk (0 risk factors)	95	40.3
Low risk (1 risk factor)	71	30.1
High risk (2+ risk factors)	70	29.6

Appendix 56

Interventions delivered by SBN for each category of psychosocial risk (n=236)

	Intervention			
Phase & risk status	**Counselling**	**Information**	**Liaison**	**Treatment**
	%	**%**	**%**	**%**
Diagnosis (n=145)				
No risk	42	92	15	0
One risk	43	87	30	0
Multiple risks	50	88	25	0
Pre-operative (n=214)				
No risk	66	91	21	0
Low risk	77	80	43	1
Multiple risk	67	82	34	1
Post-operative (n=220)				
No risk	66	85	32	10
Low risk	83	88	41	16
Multiple risk	73	84	40	5
Follow-up 1 (n=225)				
No risk	71	84	27	19
Low risk	64	88	40	15
Multiple risk	71	80	47	14
Follow-up 2 (n=219)				
No risk	66	57	16*	7
Low risk	66	66	36	4
Multiple risk	67	56	39	2

*$p<0.005$

Appendix 57

Women's GHQ-12 scores at two and six months after diagnosis

	Time after diagnosis			
	Two months		Six months	
GHQ-12 score	**n**	**%**	**n**	**%**
Low (0/1)	100	44.3	121	59.9
Borderline (2/3)	41	20.2	28	13.9
High (4-12)	62	35.5	53	26.2

Appendix 58

Psychological needs identified and referrals made by SBN during each treatment phase, based on two month GHQ-12 score

	Need		Referral
GHQ-12 Score	Psychological symptom	Any psychological need	Referral
	%	%	%
Diagnosis (n=129)			
Low	34	57	0.0
Borderline	33	56	0.0
High	47	57	2.0
Pre-operative (n=193)			
Low	46	58	1.0
Borderline	46	54	0.0
High	66	73	5.2
Post-operative (n=197)			
Low	50	64	1.0
Borderline	40	65	0.0
High	59	71	3.3
Follow-up 1 (n=201)			
Low	33	40	0.0
Borderline	53	58	1.5
High	51	58	6.2
Follow-up 2 (n=196)			
Low	28	47	2.0
Borderline	33	49	2.3
High	57*	71*	4.4

*$p<0.01$

Appendix 59

Detection of psychological needs at the follow-up 1 consultation and those initiated by women

	Women's scores		
Need	**Low**	**Borderline**	**High**
Follow-up 1 standard consultation (n=201)			
Specific psychological need recorded	33%	53%	51%
Any psychological need recorded	40%	58%	58%
Patient-initiated consultation (n=69)			
Specific psychological need recorded	38%	15%	29%
Any psychological need recorded	62%	46%	66%

Appendix 60

The financial cost of SBNs and caseload by site

SBN position: **Nurse Award classification**	**Contract hours per week**	**Pay per hour**	**Total cost per month** Including "on costs" at 23%	**Monthly caseload** New diagnosis	**Monthly caseload** Other patients
Position 1: 2 x CNC Level 2.4	45 (job share between 2 SBNs)	$21.94	$5343	34	14
Position 2: CNC Level 3, Band A, Year 2	38 hours	$25.48	$5240	36	20
Position 3: CNC	37.5 hours	$27.10	$5500	16	2
Position 4: CNC	20 hours	$24.34	$2635	27	32
Position 5: Nurse Grade 4, Level B	40 hours	$24.31	$5262	49	32
Position 6: Nurse Grade 4, Level 2	40 hours	$23.16	$5013	36	23
Position 7: CNC Grade 4, Level A, Year 1	25-30 hours	$24.00	$3247– $3897	N/A	N/A

Appendix 61

Caseload Questionnaires

At the end of each clinical consultation in the “without SBN” period, the observer asked the surgeon or nurse the following questions:

1 Do you feel that you spent longer with the patient in the breast nurse's absence?

2 If so, please estimate how many minutes longer you spent with the patient.

3 Did you spend longer providing support or counselling because the breast nurse was absent?

4 Did you provide any additional information because the breast nurse was absent?

5 If yes, what were they?

6 Did you do anything differently because the breast nurse was absent?

7 Did you offer any resources or referrals that the breast nurse would normally have organised?

At the end of each clinical consultation in the “with SBN” periods, the observer asked the surgeon or nurse the following questions:

1 Did you refer the patient to see the breast nurse?

2 On what basis/reason did you decide to refer the patient to the breast nurse?

3 By referring the patient to the breast nurse, has this freed up any of your time to do other things (eg seeing other patients) and roughly how much time does this free up?

At the end of each clinical consultation in the "with SBN" periods, the observer asked the breast care nurse the following questions:

1 How long did you spend with the patient?

2 What did you do for the patient?

3 Did you organise any referrals (for example health services and/or clinicians) for the patient? If yes, what were they?

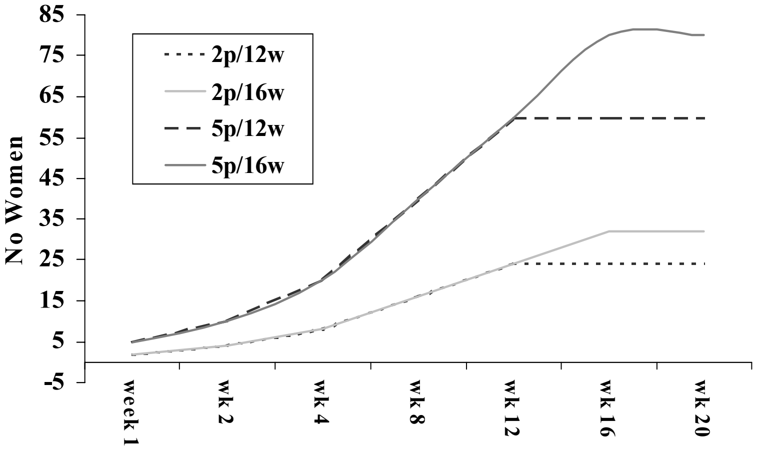
4 Did you give the patient any resources or literature? If yes, what were they?

5 Did you spend time with the patient's partner, family or support person?

6 Did you provide any additional resources or information for the family or support person? If yes, what were they?

Appendix 62

SBN cumulative caseloads



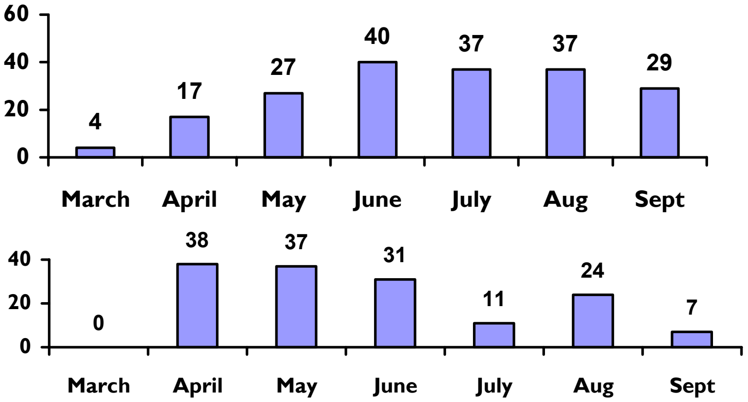
Appendix 63

SBN caseload survey: sample feedback and questions

SBN position 1

Caseload for the seven months from March to September 1998.

SBN caseload by month. Number of patients with a new diagnosis of breast cancer



The average time you spend face-to-face with “other” patients is 27 minutes per consultation. You spend about 51% of your working week on patient-related activities.

Imagine that your patient caseload consists only of women with a new diagnosis of breast cancer. You provide the same level of care and follow-up for each of these patients as you currently provide each woman who is referred to your Breast Clinic. But imagine that all your other patients (women diagnosed with systemic breast cancer, benign cancer, cancer other than breast and those women with a previous history of breast cancer) are seen by another Clinical Nurse Specialist and receive the same level of care that you would otherwise have provided. What would you do (hypothetically speaking) with the freed up time? How many additional women with a new diagnosis of breast cancer could you see each month with this freed up time?

Appendix 64

SBN caseload survey results, for five SBNs

	Response		
SBN	**Feedback**	**Estimate**	**Comments**
1	27 minutes per consultation; 51% of time spent on non-clinical activities	6-8 extra women	It is important that other institutions understand that this role is not solely confined to counselling. Education, developing policies, community involvement and continuity of care are vital to the success of the role. In terms of the “survival” of the breast nurse, it would be physically and mentally exhausting to be confined to counselling newly diagnosed patients only …
2	17 minutes per consultation; 42% of time spent on non-clinical activities	8-10 extra women	This would create a job which is almost solely counselling and would diminish my job satisfaction greatly. Numbers will always vary, greatly as some months fewer patients are diagnosed … ie some months we would be seeing as little as eight patients, and other months up to 20. Need to take account of the fact that “other” patients require little time … compared to newly diagnosed …
3	21 minutes per consultation;35% of time spent on non-clinical activities	1 extra woman	Rural sites would normally only have one SBN who would see all patients. Eliminating “other” patients would make little difference. … [E]ach woman with a new diagnosis of breast cancer would require approximately five hours over the intervention protocol. Rural sites vary enormously from urban.
4	27 minutes per consultation; 52% of time spent on non-clinical activities	5-6 extra women	The model should not stop at 10 weeks. Women have ongoing issues at this time … If we are serious about continuity of care, this should be considered. A woman has the experience of breast cancer for a lifetime; we are only recognising one aspect of that experience. What about recurrence, ending treatment, etc.
5	26 minutes per consultation; 59% of time spent on non-clinical activities	4-8 extra women	My position would be greatly enhanced by having a pre-admission clinic. My concern also by doing it this way would be that the SBN position should be along the disease continuum – what happens to these women post 12 weeks? There needs to be someone to follow these women through. Many other patients require assistance. Why should they miss out just because they don't fit this model?