Breast Care Nurses in Victoria

A Workforce Study of Practice and Factors Influencing Practice

Summary Report

Undertaken by the Victorian Centre for Nursing Practice Research,
School of Post Graduate Nursing,
The University of Melbourne

for the

***BreastCare Victoria* Coordination Unit,**
Victorian Department of Human Services.

Foreword

On behalf of the Victorian Centre for Nursing Practice Research, I am pleased to present this Summary Report of the *Breast Care Nurse Workforce Study* to the *BreastCare Victoria* Coordination Unit, Department of Human Services.

Breast cancer is the most common cancer in Victorian women and presents a major threat to the health and well being of women and their families. Breast cancer has serious implications for both the physical and psychological health of women. The way in which they are treated and the support they receive from breast care services can have a significant impact on their experience.

The value of the specialist breast care nurse role as part of the multidisciplinary team in providing quality care for women has been increasingly recognized nationally and internationally as part of evidence-based best practice for breast care.

In Victoria nurses have played a valuable role in providing breast care services to Victorian women over the past two decades. However a woman's access to a specialist breast care nurse remains varied, depending on the setting in which she is treated.

In 2000 the Victorian Centre for Nursing Practice Research was commissioned by the Department of Human Services to undertake the *Victorian Breast Care Nurse Workforce Study*. The study provides a comprehensive view of the role and practice of breast care nurses across Victoria in late 2000. The commitment of Victorian breast care nurses to enhance care for women is reflected in their willingess to participate in the study and their desire to be involved in service improvement.

This Summary Report highlights the key findings of the study and aims to generate discussion with key stakeholders, inform current efforts to improve breast care nurse services and assist in future service planning and evaluation. It also provides an opportunity for Victorian breast care nurses to lead the way in future endeavours.

It is hoped that this Report will be the catalyst for a service-wide discussion of the identified issues and a collaborative effort to ensure that the valuable breast care nurse resource is used to maximise the health outcomes of women with breast cancer.

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Introduction—Breast Care Nursing in Victoria

The breast care nurse role has been widely recognised as an important feature of quality multidisciplinary breast care services. In Victoria, the role of the breast care nurse has been promoted for more than 20 years by the Anti-Cancer Council of Victoria through its Breast Cancer Support Service.

In 1997, the first tertiary level Breast Care Nurse Distance Education Program was implemented as a joint initiative of La Trobe University and the Anti-Cancer Council of Victoria. This 12-week program is accredited by the Royal College of Nursing, Australia. Participation in ongoing educational and support opportunities is an essential requirement of being recognised as an 'accredited' breast care nurse with the Anti-Cancer Council of Victoria.

In 1998, a Victorian breast services mapping exercise was completed by 50 per cent of all Victorian public and private acute services [1]. This exercise provided a partial picture of the nurses available for women with breast cancer. It also indicated that the nurses had various titles and roles and were available in hospitals, through the Royal District Nursing Service or through links with other hospitals.

In 1999, the *BreastCare Victoria* Coordination Unit was established within the Department of Human Services to oversee the implementation of the *Breast Disease Service Redevelopment Strategy 1999–2001.* The *Strategy*, developed through extensive consultation with key stakeholders, including consumers, clinicians and other service providers, identifies that treatment for breast cancer is variable and fragmented, and that change is needed. It outlines key action areas for redevelopment to improve: equity of access to high quality services for all women; the capacity of services to be responsive to client needs; the implementation of an evidence-based approach to breast cancer management; and the translation of research into clinical practice.

Based on current evidence of best practice [2] [3], the *Strategy* also identified the importance of the breast care nurse in the management of women with breast cancer. In particular, the *Strategy* identified the need to:

- Promote the provision and role of breast care nurses in acute settings
- Facilitate the role development and training of breast care nurses.

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[1] Breast Care Implementation Advisory Committee. 1999. *Breast Disease Service Redevelopment Strategy*. Melbourne. Victorian Government Publishing Service.
[2] Jary, J, Franklin L. 1996. The role of the specialist nurse in breast cancer. *Professional Nurse*. 11 (10) 664-5.
[3] Poole, K. 1996. The evolving role of the clinical nurse specialist within a comprehensive breast cancer centre. *Journal of Clinical Nursing*. 5 (6): 341-9.

An important component of the current *Breast Services Enhancement Program,* a major intiative of *BreastCare Victoria*, is to improve women's access to breast care nurses. Through the *Breast Services Enhancement Program*, a range of initiatives are currently being implemented, which aim to strengthen breast care nurse practice.

The Study

Aims

In 2000, the Victorian Centre for Nursing Practice Research located at the University of Melbourne was commissioned by the *BreastCare Victoria* Coordination Unit of the Department of Human Services to undertake the *Victorian Breast Care Nurse Workforce Study.* This study expands on the 1998 mapping exercise to provide a comprehensive picture of breast care nursing practice in Victoria.

The *Victorian Breast Care Nurse Workforce Study* describes the current availability and scope of practice of breast care nurses in Victoria and aims to:

- Map existing breast care nurse resources in Victoria.
- Describe the current roles and functions of breast care nurses in Victoria.
- Document variability in the roles and functions of breast care nurses and to analyse those factors influencing this variability, such as the context of care, organisational structure and support, nurses' educational preparation and professional development.
- Identify how the role of the breast care nurse currently links with the role of generalist and other specialist nurses and other health professionals.
- Identify and quantify issues that influence and have an impact on the role of breast care nurses in Victoria.

Methods

The study was overseen by an external Reference Group including breast care nurses, nurse educators and managers, a consumer, a medical oncologist and other key agency representatives, and an internal Steering Committee from the Victorian Centre for Nursing Practice Research (see Appendix 1 for Reference Group and Steering Committee membership). The Reference Group provided advice on the study design and implementation while the internal Steering Committee was responsible for project management.

The study was conducted in three phases, with Phases Two and Three overlapping.

Phase One —Planning and Protocol Development

This phase involved:

- Discussion and negotiation with stakeholders including breast care nurses, consumers and clinicians.
- A literature review.
- Development of instruments for data collection.

The main purpose of this stage was the development of appropriate protocols and instruments for data collection including the development of a suitable instrument to survey breast care nurses, refinement of qualitative approaches and the identification of key informants.

Phase Two—Data Collection

This involved determining the scope and effects of the breast care nurse role on consumers and other health professionals through the collection of quantitative (questionnaires, activity sheets, diaries) and qualitative data (focus groups and telephone interviews with breast care nurses, and in-depth interviews with key stakeholders).

Questionnaire

The questionnaire was developed collaboratively with the reference group and was pilot tested by six independent nurses to ensure face and content validity.

The questionnaire covered the following areas: demographic data including role title, area of practice, hours of work and educational preparation; role scope; role barriers and facilitators; referrals both to and from the breast care nurse; and areas for role improvement.

The questionnnaire was completed by 153 breast care nurses reflecting a 52% response rate. Data from 129 questionnaires was analysed (23 questionnaires were excluded because the respondent worked in an area in which they did not use their breast care nursing skills, and one was excluded because very limited information was provided). The 129 respondents included 53 classified as working in a dedicated breast care nurse role and 76 respondents classified as being in a non-dedicated breast care nurse role.

Activity Sheets

The activity sheets were sent out with the questionnaire and sought to capture a more detailed picture of breast care nurses' daily activities.

The activity sheets were completed by 73 breast care nurses representing 274 days of breast care nurse practice. A total of 782 patient contacts were recorded. The data from the activity sheets did not distinguish between dedicated and non-dedicated respondents, or between rural and metropolitan respondents.

Diaries

The diary was intended to capture more comprehensive and complex aspects of daily practice by a selected group of breast care nurses working in different settings. Diaries were completed by nine breast care nurses, three rural and six metropolitan, capturing 40 days of breast care nurse practice.

Focus Groups

Four rural and four metropolitan focus groups were conducted involving 44 participants. The focus groups sought to:

- Gain further insight into the scope and variation in the breast care nurse role.
- Explore factors that contributed to variability.
- Explore breast care nurse links with other health professionals.

Stakeholder Interviews

Interviews were conducted with 27 participants including medical specialists, general practitioners, other general and specialist nurses, nurse managers, other health professionals and consumers.

The interviews sought to canvas a range of perspectives from these stakeholders including access to a breast care nurse, satisfaction with breast care nurse services, gaps in service delivery, referral and liaison mechanisms, role overlap and areas for improvement and future innovation.

Phase Three—Presentation and Validation of Findings

This phase involved consultation with key stakeholders to confirm the findings of the study. Data was presented to and discussed with:

- The Reference Group
- A group of breast care nurses at a networking meeting
- Consumers, via a Breast Cancer Action Group meeting
- Breast Services Enhancement Program staff
- Participants at the Third National Breast Care Nurses Conference.

The Findings

The results of the study raised many important issues and key points for further consideration. These are described under the following headings:

1. Context of Practice.
2. The Role as Practised.
3. Models of Care.
4. Factors Influencing the Role.

The data was analysed to identify any differences between the scope and practice of nurses in dedicated roles and those in non-dedicated roles. Where there were differences between the two groups, these are highlighted in this report.

1. Context of Practice

The context of practice for breast care nurses incorporates data on role heterogeneity, identity and commitment. The study found marked variation in job title, hours of work, level of education and role scope within the breast care nurse workforce.

The title of ‘accredited breast care nurse’ is used frequently throughout the service system and implies a common level of role preparation, role scope and role implementation that was not evident in this study.

Educational Preparation

There was considerable variation in the level of education held by breast care nurses with no identified consensus on the minimum educational qualification required to practise in the role.

Of the 153 respondents, 74% had completed the Accredited Breast Care Nurse Program offered jointly by La Trobe University and the Anti-Cancer Council (See Table 1). Nine (17%) of the respondents who were working in a dedicated role had not completed this program.

Table 1. Educational Preparation

Qualification	All Respondents n = 153 %	In Dedicated Role n = 53 %
Accredited Breast Care Nurse Program	73.9	83
General Nurse Certificate	86.9	86.3
Bachelor of Nursing – pre-registration	8.5	9.4
Bachelor of Nursing – post-registration	22.9	26.4
Postgraduate Diploma – Cancer Nursing	16.3	13.2
Postgraduate Diploma – Other	24.8	26.4
Masters of Nursing	1.3	1.9
Masters – Other	2.6	1.9

Forty one per cent of the breast care nurses had a postgraduate diploma. Of these, 25 (seven in a dedicated breast care nurse role) held this qualification in a cancer related field. This is an important finding given that the population these nurses serve all have cancer.

Finally, grade of employment was not related to educational preparation and in some cases may be more related to other roles. As a result of this variation, the incentive to undertake higher degrees is diminished.

Job Title

Data from the questionnaires and diaries revealed at least 14 different titles being used by nurses involved in breast care. Examples include breast care coordinators, breast care liaison nurse, clinical nurse consultant, clinical nurse specialist and mixed roles such as Associate Nurse Unit Manager/breast care nurse or breast care nurse/stomal therapist.

Table 2 summarises data from the 153 breast care nurses responding to the survey in terms of current practice. Only 35% of respondents (n=53) currently work in areas where they have time dedicated to a breast care nurse role, with some of these also using the title ‘breast care nurse’. Thus, many nurses self-define as breast care nurses or have completed the accredited breast care nurse course but are not working in a dedicated breast care nurse role.

Table 2. Breast Care Nurse Role Summary (n=153)

Respondents' Role	Percentage (n)
Time/Title in dedicated role	35% (53)
Cancer support role	10% (16)
Area where patients have breast cancer	39% (60)
Currently not using breast care skills*	15% (24)

- Excluded from subsequent analysis

Hours of Work

The range of hours worked in the breast care nurse role ranged from 0 to 40 hours per week. Of the 75 respondents who answered this question, 40 (53%) worked less than 10 hours per week in the breast care nurse role. Fifty-nine (45%) respondents reported that they were the only breast care nurse within their organisation.

Role Setting

Of the 129 questionnaire respondents currently using their breast care skills:

- 93 (72%) reported working in a public setting
- 33 (26%) reported working in a private setting
- 66 (51.2%) worked in the metropolitan area
- 60 (46.5%) worked in a rural region.

There was missing data for three respondents.

Commitment to the Role

The nurses interviewed for the study expressed a strong commitment to the care of these women and to ensuring that all women have access to a breast care nurse. Focus group data indicates breast care nurses:

- Alter their working days and hours to ensure they are available to see women.
- See women out of hours.
- Employ a variety of methods to ensure they are aware of all women diagnosed with breast cancer. For example, making friends with admission staff/booking clerks, liaising with staff in peri-operative services or allied health services or talking with staff from retail outlets that supply breast prostheses.

The breast care nurses were aware of many of the issues identified throughout this report and expressed a desire to be involved in service improvement. For example, breast care nurses readily identified gaps in the service they provided. Many expressed a strong desire to improve their care of women and are committed to role development.

Role Identity

The strong role identity of breast care nurses must be attributed, at least in part, to the work of the Anti-Cancer Council of Victoria. Breast care nurses constantly highlighted the coordination, education and support role of the Council as a major factor that sustains them in their role. However, clear difficulties were identified with use of the term 'accredited breast care nurse' rather than a breast care nurse who has undertaken an accredited course of study.

Context of Practice - Points for Consideration

- Job title consensus should reflect industrial, educational and organisational standards.
- The title '*breast care nurse'* needs to be protected to ensure an appropriate level of educational preparation and practice.
- The Anti-Cancer Council plays an important role in professional development of the breast care nurse workforce.
- The term 'accreditation' should be limited to programs of study rather than to indicate accreditation of individual practitioners.
- Breast care nurses are willing to critically examine and change their practice if the outcome is improved care of women with breast cancer.

2. The Role as Practised

The study illustrated the variability in the way the breast care nurse role is practised across Victoria. This was highlighted by the variations in:

- Role conceptualisation
- Sources of referral to breast care nurses
- The role in coordination of care
- The role within the multidisciplinary team
- Nature of consultations
- Provision of information
- Provision of psychological support.

Role Conceptualisation

Two images of the breast care nurse role were identified through the focus group data:

- The breast care nurse as empowering the woman to be her own advocate (the empowerment role).
- The breast care nurse feeling it is her responsibility to do everything for the woman (the do everything role).

These images can co-exist but one is usually dominant in each nurse's practice. The following quotes illustrate the differing role conceptualisation:

The empowerment role:

With any patient contact my aim is to enable them to be their own advocate, so they know where to get information. If they get stuck along the continuum then I'll be there for support.

The do everything role:

What I provide is a service, practical and emotional support, understanding breast prosthesis because they need that…I say to them 'look if you've got any questions you don't know who to ask, ask me…I'll sort them out.

While elements of both role concepts are important to the care of women with breast cancer, the do everything role may limit the degree to which the breast care nurse involves others. This role concept may also link to the low levels of referral from the breast care nurses and low levels of participation in multidisciplinary teams.

In line with this role concept, several stakeholders indicated the need for the breast care nurse to pass on knowledge and skills to other nurses, rather than trying to protect her role by keeping the expertise to herself. This perceived lack of skill development in other nurses resulted in sub-optimal levels of information and support provided to women when the breast care nurse was not available.

Sources of Referral to Breast Care Nurses

The most common source of referrals for breast care nurses came from surgeons and surgical nurses. Referrals from other health professionals, such as radiation oncologists, were infrequent (See Table 3).

Table 3. Referral to Breast Care Nurse by Source (n = 129)

Source of Referral	Frequently	Occasionally	Never
Surgeon	47	40	28
Medical Oncologist	8	29	59
Radiation Oncologist	5	13	77
General Practitioner	4	41	54
Surgical Nurse	49	30	26
Medical Oncology Nurse	14	28	50
Radiation Oncology Nurse	6	11	72
Cancer Helpline	0	23	71

Breast care nurses in a dedicated role were more likely than those in a non-dedicated role to frequently receive referrals from:

- surgeons (59% dedicated vs 21% non-dedicated)
- a surgical nurse (47% vs 32%)
- a medical oncology nurse (19% vs 5%).

Half of the respondents who frequently received referrals from surgeons reported that it was usual practice to sit in on consultations between the patient and the surgeon. This suggests that joint consultation may be an effective way to ensure breast care nurse involvement.

Four of the nine breast care nurses keeping a diary received referrals during the diary-keeping period. Of the total referrals (n = 17), eight were self-referrals, five were from surgeons, two from medical oncologists and two from radiation oncologists, consistent with the overall findings about referral.

As a result of the limited referral to breast care nurses, the majority of women were located at, or soon after, diagnosis through the breast care nurses' own knowledge of the local environment. Some women heard about breast care nurses through word of mouth and so referred themselves.

In terms of standards of practice, it is clear that at the time of the study, referral to and consultation with a breast care nurse was not yet a routine part of care following diagnosis with breast cancer in many settings. This is in contrast to the emerging

recognition of the importance of the breast care nurse role in national guidelines such as the Psychosocial Clinical Practice Guidelines [4]

The Role in Coordination of Care

The role of breast care nurses in coordinating care for women with breast cancer was highlighted in both the questionnaire and focus group discussions. One breast care nurse described her coordination role as being:

….like a pivotal contact person throughout each of their (women's) major contact visits across the continuum of care.

Despite this view, the study results suggest that the breast care nurse role in working with and involving other health professionals in women's care was varied.

The questionnaire data revealed that breast care nurses were more likely to be involved in joint consultations with the surgeon; 33 (25%) respondents reported that this happened frequently. The majority of these joint consultations occurred on the ward round. However, it was occasionally reported that these consultations occurred on an ad hoc basis, depending on whether the breast care nurse was working or available. To maximise the opportunity for joint consultation, many breast care nurses reported scheduling their working hours to ensure their availability.

Joint consultations were also reported on a routine basis when the breast care nurse was present in pre-admission or outpatients clinics. The breast care nurse tended to be the person who organised or initiated these joint consultations.

Breast care nurses reported that they were rarely involved in joint consultations with a medical oncologist or radiation oncologist.

Linkage with other health professionals was also identified as an important role of the breast care nurse. The frequency of referral to, or consultation with, other service providers by the breast care nurse is summarised in Table 4.

[4] NHMRC National Breast Cancer Centre. 2000. Psychosocial Clinical Practice Guidelines for Providing Information, Support and Counselling to Women with Breast Cancer. Canberra. NHMRC.

Table 4. Frequencies (%) of Breast Care Nurse Referral to, or Consultation with, Another Service Provider (n=129)

Service Provider	Frequently	Occasionally	Never	*Not available	Missing Data
Cancer Helpline	50.3	36.4	4.7	1.6	7
Physiotherapist	39.5	42.6	7	1.6	10.1
Breast Cancer Support Service Volunteer	37.9	36.4	14	3.9	8.5
Social Worker	31	45	7.8	6.2	10.9
Breast Care Nurse in Another Department or Institution	28.7	52.7	9.3	0	10.1
Chemotherapy Nurse	26.4	31.8	18.6	5.4	20.1
Community Nurse	23.3	41.8	14.7	3.9	20.7
Lymphoedema Clinic	20.1	51.6	9.3	7.8	14
Palliative Care	14	45.7	23.3	3.1	17.1
General Practitioner	13.2	51.9	20.1	3.1	13.2
Radiotherapy Nurse	11.6	17.1	33.3	22.5	17.1
Pastoral Care	10.9	46.5	20.9	8.5	15.5
Occupational Therapist	10.1	31.8	38.8	7	16.3
Counsellor	7	53.5	23.3	11.2	12.4
Religious Worker	3.9	38	34.9	10.9	14
Psychologist	3.9	31	36.4	14.7	16.3
Psychiatrist	1.6	17.1	51.6	13.2	21
Cultural Worker	0.8	21	41.9	21.7	17.1
Diversional Therapist	0	4.7	50.3	28	21.7

* Not available: indicates that this resource person was not available in the setting in which the breast care nurse was practising.

Fifty per cent of all breast care nurses indicated that they frequently referred women to the Anti-Cancer Council's Cancer Helpline. In addition, between 30–40% of all breast care nurses reported frequently referring to, or consulting with, physiotherapists (39.5%), a Breast Cancer Support Service volunteer (38%), or a social worker (31%). Almost 30% of breast care nurses reported communicating frequently with a breast care nurse in another department or institution.

Breast care nurses in dedicated roles were more likely to frequently refer to the Cancer Helpline, a Breast Cancer Support Service volunteer, a chemotherapy nurse or a lymphodoema clinic than those in non-dedicated roles (see Table 5). These differences were statistically significant.

Table 5: **Differences in Frequency of Referrals to, or Consultation with, Other Service Providers by Breast Care Nurses in Dedicated or Non-Dedicated Roles**

	Percentage of Breast Care Nurses Who Frequently Refer or Consult with Another Service Provider		
Service Provider	**Non-Dedicated BCN Role %**	**Dedicated BCN Role %**	
Cancer Helpline	50.3	69.8	p=0.04
Breast Cancer Support Service Volunteer	37.9	50.9	p=0.017
Chemotherapy Nurse	26.4	39.6	p=0.03
Lymphodoema Service	20.1	26.6	p=0.001

However, consultation and referral by all breast care nurses to some professional groups was more limited. While this may reflect the limited availability of other professionals, particularly in rural areas, this does not fully explain these results. There appears to be scope to further develop this area of practice to ensure that women are able to access resources in a timely and appropriate manner.

The referral by breast care nurses to health professionals with skills in providing psychosocial and emotional support particularly needs strengthening. In the study nurses identified the provision of psychosocial and emotional support as central to their role and identified the need for more education in this area. However, even when available, there were low rates of referral to other health professionals with the specific skills, such as counsellors, psychologists and psychiatrists.

These low referral rates to specialist counselling services are of some concern given the known psychological morbidity experienced by women following breast cancer. A recent

Australian study demonstrated that 29% of women suffered from significant adjustment problems and had depressive and/or anxiety symptoms at three months post-surgery [5].

The Role within the Multidisciplinary Team

The study results indicate relatively low levels of involvment by breast care nurses in multidisciplinary teams. This was reflected in all aspects of the data collection and was reinforced by the views of other stakeholders.

Thirty-seven per cent of all breast care nurses reported involvement in multidisciplinary meetings (40% of nurses in a dedicated role compared with 34% in a non-dedicated role); overall their role was varied and included patient advocacy, input into patient care discussion and providing psychosocial information.

However, many breast care nurses reported that a major aspect of their role was in the administration of these meetings. Other stakeholders, such as medical specialists, voiced concern that the breast care nurses often have limited input into the meetings they attended, although the reasons for low involvement were uncertain. It may reflect the different levels of inclusion and value of the breast care nurse by other members of the multidisciplinary team. A breast care nurse who felt valued within the team said:

From the meetings that we've had I think the clinicians [medical specialists] are now valuing our contact with women, and are actually asking us often where this woman is at or if there's anything else that we know about the woman.

Not surprisingly, those who did not feel valued were not included in the team:

They don't even know what I do much less value me…the rest of them [the multidisciplinary team] think that all I do [is] fit the prosthesis for them, that's it.

Nature of Consultations

Based on the questionnaire data, the only routinely performed physical activities, conducted by more than half of the participants, were fitting of temporary prostheses, removal of drains and sutures and wound assessments/dressings (see Table 6).

However, 83% of breast care nurses in dedicated roles reported fitting prostheses, compared with less than half of nurses in a non-dedicated role. This was statistically significant ($p=0.005$).

These results were reinforced by the activity sheet data and reflect the practical and technical focus of the role.

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[5] Kissane DA, Clarke DM, Ikin J, et al. 1998. Psychological morbidity and quality of life in Australian women with early-stage breast cancer: a cross-sectional survey. *Medical Journal of Australia*. 169:192–196.

Table 6. Routine Activities—Questionnaire Data

Activity	Respondents (%)
Wound Assessment	63.6
Fitting/Provision of Temporary Prosthesis	60.5
Wound Dressings	59.7
Removal Drains/Sutures	46.5
Treatment/Assessment of Lymphoedema	31.8

Provision of Information

A major role of the breast care nurse is to provide information, in particular relating to the care of women at diagnosis and pre- and post-operatively. This aspect of the breast care nurse role was reflected in the questionnaire data. However, variations in information provided were also noted with access to resource materials a likely contributing factor.

Encouragingly, more than 75% of all breast care nurses, regularly provided information on one or more of the following areas during their consultations with women:

- Practical support (however this finding from the questionnaire data was not supported by diary data)
- Adjuvant treatment—what it is and what to expect
- Dealing with symptoms/side effects
- Lymphoedema
- Sexuality/body image
- Breast prosthesis
- Breast Cancer Support Service
- Cancer Helpline
- Support groups.

There were no differences in these areas of information provision between nurses in dedicated and non-dedicated roles.

Fifty to 75% of all breast care nurses regularly provided information on one or more of the following areas during their consultations with women:

- Diagnosis
- Treatment choices
- Multidisciplinary care
- Surgery—what it is and what to expect
- Results of surgery

- Breast reconstruction
- Financial issues
- Care of the wound/drain tube at home
- Discharge and treatment plan
- Ongoing screening.

In these areas of information provision, breast care nurses in a dedicated role were more likely than those in a non-dedicated role, to regularly provide information to women about:

- treatment choices (83% dedicated vs 53% non-dedicated)
- multidisciplinary care (83% vs 61%)
- surgery – what it is and what to expect (83% vs 58%)
- breast reconstruction (87% vs 53%)
- discharge and treatment planning (70% vs 36%)
- ongoing screening (81% vs 40%).

Less than 50% of all breast care nurses regularly provided the following information:

- Prognosis
- Genetic counselling
- Palliative care
- Clinical trials
- Advocacy groups.

In these areas of information provision, breast care nurses in dedicated roles were more likely to regularly provide information on genetic counselling than those in non-dedicated roles (45% vs 16%). Breast care nurses in a non-dedicated role were more likely to regularly provide information on palliative care than nurses in a dedicated role (49% vs 30%).

Breast care nurses were also asked about the provision of specific resources for women. Approximately 90% of all respondents provided general materials about breast cancer and treatment. Between 50-60% regularly provided printed material in other languages, general material about treatment completion and specific resources on support services. Approximately 30% of respondents regularly provided audio/video tapes about breast cancer and treatment. Two respondents provided a tape recording of their consultations with women on a regular basis.

The key stakeholders affirmed the role of the breast care nurse in providing information. This was commonly described as an important component of the supportive role of breast care nurses. In addition, nurses in day chemotherapy wards felt that the information provided to women by the breast care nurse did not replace the information they needed to provide, but made their role easier, for example:

Women who have seen a breast care nurse have a better overall understanding of what is going on than those who haven't seen a breast care nurse.

Provision of Psychological Support

Consistent with the national and international literature on the role of the specialist breast nurse, breast care nurses and key stakeholders identified the provision of psychological support as an integral component of the breast care nurse role [6] [7].

Medical stakeholders, in particular, felt that the provision of emotional support by the breast care nurse was very important and of great benefit to the doctor. For example, one doctor said:

The breast care nurse has time to sit with the patient and listen and provide emotional support and that's time I don't have.

The study revealed that 75% of all breast care nurses provided emotional support to women with 53% providing social support. This was provided both face-to-face and by telephone, although no respondents indicated that they provided emotional support by telephone alone. Significantly more respondents in a dedicated role reported providing both face-to-face and telephone emotional support (p=0.0005) and social support (p=0.002) than those in non-dedicated roles.

However, through issues identified in this study, there is a need to articulate the difference between the provision of general emotional support through therapeutic communication (active listening, problem identification and advice) versus the need to identify specific psychological issues requiring referral for specialised intervention. As one stakeholder put it:

….I think [therapeutic communication] is actually being able to use empathy and hear a person, hear the issues and then be able to assess what they are saying their needs are, and I wouldn't put that lightly at all, it takes enormous skill to do that ….counselling is being able to in many ways challenge what someone is telling you about why they are distressed to enable them to actually move on, to actually have a goal when you are working with someone, to move them from one place to another, and I think that actually requires another skill.

These two distinct but related aspects of psychological support appear to be confounded in the implementation of the breast nurse role. Importantly, respondents did not identify the assessment of psychological issues as a routine component of the breast care nurse role. Twenty per cent (n=27) of all breast care nurses indicated that they ever assessed

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[6] Specialist Breast Nurse Project Team 2000. *Specialist Breast Nurses: An Evidence-Based Model for Australian Practice*. iSource National Breast Cancer Centre.
[7] NHMRC National Breast Cancer Centre 2000. *Psychosocial Clinical Practice Guidelines for Providing Information, Support and Counselling to Women with Breast Cancer*. Canberra: NHMRC.

women's psychological status. Of these 27 breast care nurses, 18 routinely assessed the woman's psychological status with nine using a formal assessment tool.

Many breast care nurses identified the need for counselling education. However, as a group, they appeared not to make full use of their capacity to refer women to counselling and psychosocial professionals.

These results suggest that the provision of psychological support needs further development within breast care services and that breast care nurses require enhanced therapeutic communication skills. Such skills will further enhance their capacity to offer emotional support, to appropriately identify women with significant psychological issues and to refer these women to relevant psychological services.

The Role as Practised – Points for Consideration

- An agreed role definition and scope of practice is needed that is responsive to the needs of women with breast cancer and operates within an effective multidisciplinary environment.

- Breast care nurses require further development to maximise their contribution to the multidisciplinary team and to enhance their linkages with, and referrals to, other health professionals / service providers. At the same time, increased acknowledgement of the value and contribution of the breast care nurse to the multidisciplinary team is needed by other team members.

- A significant aspect of the breast care nurse role is the provision of information and emotional support. Breast care nurses require further skill preparation to assist in their role in the wider implementation of the NHMRC *Psychosocial Clinical Practice Guidelines*. These skills include psychosocial assessment, therapeutic communication and referral.

3. Models of Care

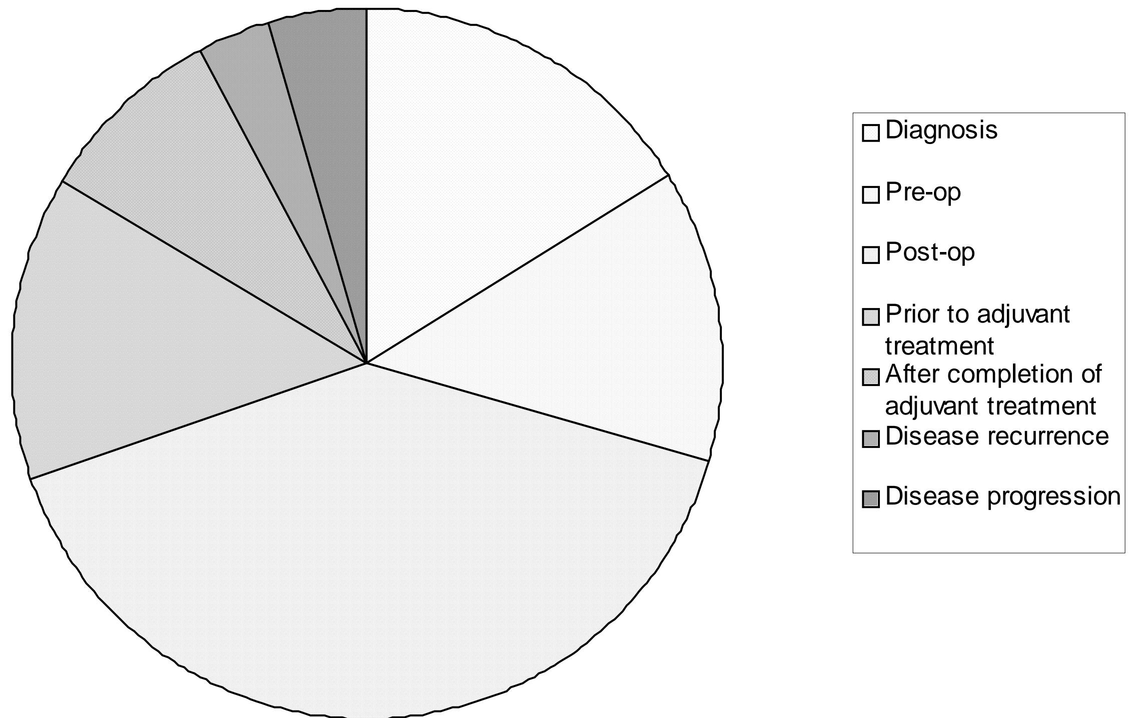
Evidence of a clinical pathway was present in the data collected through the Activity Sheets. However, nurses did not clearly articulate this pathway when asked to describe their own role.

Women were most likely to be seen on a routine basis by a breast care nurse in the diagnostic phase and in the pre- and post-operative periods (see Figure 1), particularly if the breast care nurse was in a dedicated role. However, the data also indicated variations in terms of the content and function of these contacts as outlined earlier (see The Role as Practised).

The average contact time ranged from 19 to 39 minutes (see Figure 2). In the management of newly diagnosed women, the average time of contact was 30 minutes at time of diagnosis with shorter average times at the pre-and post-operative contacts.

While only a small proportion of breast care nurse contacts were with women with disease recurrence, the average contact time was the longest at 39 minutes.

Fig 1. Percentage of contacts per stage in illness trajectory



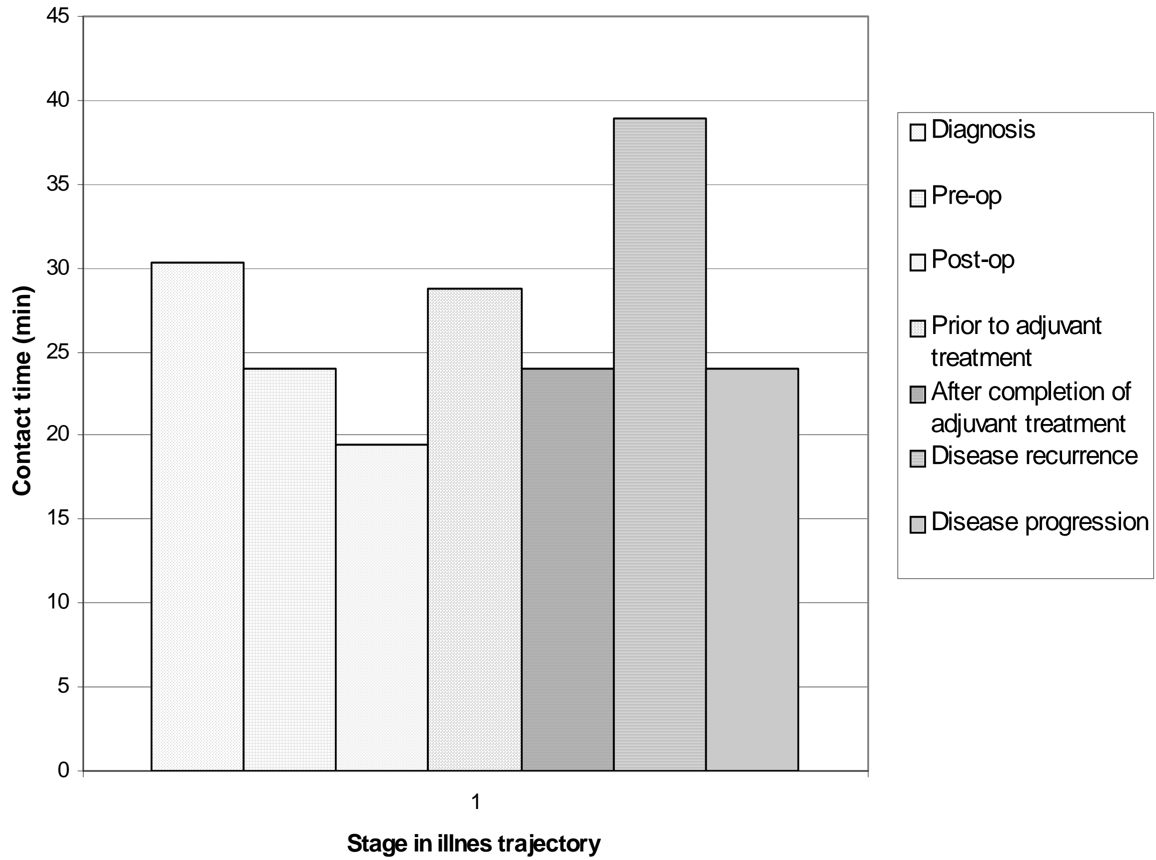


Fig 3. Average time of contact per stage in illness trajectory
Contact time (min)
45
40
35
30
25
20
15
10
5
0
1
Stage in illnes trajectory
Diagnosis
Pre-op
Post-op
Prior to adjuvant treatment
After completion of adjuvant treatment
Disease recurrence
Disease progression

Gaps in Services Provided by Breast Care Nurses

Access to a breast care nurse appears to vary according to hours worked, the hospital where the woman is treated and the level of support for the breast care nurse role by the woman's treating doctor.

Several gaps in the provision of breast care nurse support were identified. Of most significance was that the majority of breast care nurses, in both dedicated and non-dedicated roles, infrequently and only on an ad hoc basis, saw women:

- During adjuvant treatment
- During follow-up after treatment
- At the time of recurrence or disease progression
- With advanced disease.

Other gaps identified related to particular groups of women or services available in the local area. Groups of women who may not benefit from the breast care nurse role include:

- Koori women
- Women from a non–English-speaking background
- Elderly women
- Young women
- Women having hormonal therapy
- Women having procedures in a day surgery setting.

At least some of these gaps are likely to be a function of location of the breast care nurse within surgical units, inadequate hour allocation to the role, along with a role preparation that does not include a broader focus on the care of people with cancer.

In some settings, particularly in rural Victoria, breast care nurses identified tensions in providing services to breast cancer patients and not to patients with other cancers. This suggests that a broader cancer support role may be more appropriate where the number of women treated with breast cancer is small.

The study results reflect some limitations of applying the breast care nurse role from within a narrow framework or from a single role description. Discussion is needed on whether the breast care nurse role is the most appropriate to meet the needs of women across the entire illness pathway. Breast care nurses do, however, need to have a clear understanding of the entire pathway and as care coordinators are a key point of referral for women needing access to other health services.

Models of Care – Points for Consideration

- A clear pathway of the breast cancer trajectory and required intervention points should be used to guide the support offered to women with breast cancer by both the breast care nurse and other health professionals. This pathway must be based on women's needs.
- The pathway needs to be supported by exemplary communication mechanisms between various health services and departments within each service, including team review and consultation.
- This pathway should guide a consistent policy of service provision using flexible models of service delivery appropriate to local need.
- Education and training programs need to be enhanced or developed to complement the emerging pathway of care for women with breast cancer.
- Consideration needs to be given to the scope of the breast care nurse role. For instance, after a particular point in the disease continuum, for example diagnosis of advanced disease, the care of women may need to be transferred from the breast care domain to a cancer care domain.
- Pathway development and new models of breast care nursing practice should draw on the work being undertaken in Victoria as well as national and international experience.

4. Factors Influencing the Role

The study revealed several factors that influenced the breast care nurse role, such as the nurses' knowledge base, their understanding and participation in clinical supervision, and the qualities and degree of involvement of the individual nurse, the team and the organisation/management.

Knowledge Base

As highlighted earlier, the educational preparation of breast care nurses varies. While most nurses self-identifying as breast care nurses had undertaken the accredited breast care nurse program, there was general acknowledgement that this did not fully prepare them for specialist practice.

The practice setting also had an impact on the breast care nurses' level of knowledge. Nurses who saw small numbers of women with breast cancer and worked outside of a specialist setting expressed concerns about their ability to remain up-to-date in the field. There was also evidence that some breast care nurses held outdated or incorrect information about services available, for example the provision of prostheses to women in the private setting.

Clinical Supervision

There was limited overt acknowledgment by breast care nurses of the potential stressors associated with working in isolation with a vulnerable group of women and the possible need for support or debriefing for themselves. This view was reinforced by the lack of recognition and undervaluing of the breast care nurse role within the workplace.

However, the concept of, or the need for, clinical supervision was not understood or identified by many respondents. Of those who did understand the need for clinical supervision, inability to identify or access appropriate personnel was reported.

Other Factors

Other factors identified as encouraging or hindering the breast care nurse role include:

- **The individual nurse**

Many breast care nurses identified themselves as key promoters of the role. However, other breast care nurses recognised limitations in their preparation for, and experience in, the role. This influenced the way they practised. This was particularly true in areas treating small numbers of women and the breast care nurses were concerned about their capacity to keep up-to-date.

- **The team**

An understanding and recognition of the breast care nurse role by multidisciplinary team members as an essential component of care for women with breast cancer, greatly encouraged practice. When members of the team lacked this understanding and recognition, the breast care nurse's role and practice was hindered.

- **The organisation/management**

Breast care nurses felt best able to develop their role to its full potential when management recognised the importance of the role and actively promoted it within the organisation. Barriers were experienced when management placed restrictions on breast care nurses by not allowing them to see women after discharge, restricting their working hours and allocating time to the role that did not match the workload. As a consequence, many breast care nurses, particularly in rural areas, felt torn between their commitment to support women and the organisational constraints. As a result, some breast care nurses saw women in their own time or worked unpaid overtime.

Other barriers arose when women were treated in multiple sites while the breast care nurse was employed by one institution and prevented from working across sites.

Financial support for continuing education was seen as particularly helpful for role development. Unfortunately, in some settings this kind of support was lacking as was leave replacement. The role of the Anti-Cancer Council in providing ongoing education

was a significant facilitator of practice for many breast care nurses, particularly those with little access to other forms of professional development.

The study also highlighted specific barriers for breast care nurses in rural practice. Rural women are more likely to have to travel long distances to see a breast care nurse and are less likely to have a face-to-face consultation. Rural breast care nurses were more likely to be supporting women they knew in their local communities. Coordination of care was also more complex in rural areas as women were more likely to be treated in both metropolitan and rural centres with communication between settings not always ideal.

Finally rural breast care nurses were particularly concerned about their ability to keep up-to-date and the costs of attending Melbourne-based education.

Factors Influencing the Breast Care Nurse Role – Points for Consideration

- Breast care nurses require a supportive working environment, positive collegial and management relationships and self-confidence in order to practise their role to a satisfactory degree.
- Breast care nurses need enhanced skills to raise their profile with stakeholders, to be better able to contribute to multidisciplinary care planning and to demonstrate their role in improved outcomes.
- Lack of recognition by team members, limited access to resources, limited hours in which to conduct the role, and small throughput limits the breast care nurse's capacity to adequately respond to the needs of women with breast cancer.
- The potential occupational health and safety and insurance issues arising from breast care nurses' current unpaid work need to be examined.
- Policy and structural changes are needed to ensure that clinical supervision is made available to breast care nurses, particularly those in dedicated roles. This may have a positive influence on retention of the breast care nurse workforce.

Future Directions

Breast care nurses are an increasingly important component of comprehensive cancer care services offered to women with breast cancer. However, this study reflects that the current workforce lacks a common approach to women and that role development has occurred in an ad hoc and variable manner. This means that the service women receive from the breast care nurse may vary according to the site of their care and the treatment they receive.

The results of this study suggest that breast care nurses are ready and willing to engage in change but the effort will require some central coordination and leadership. A number of key documents, principally the NHMRC guidelines for early and advanced breast cancer and for psychosocial support of women with breast cancer, offer significant direction for this change.

In addition, future development needs to be informed both by current Victorian breast care nurse initiatives and broader nursing directions. Finally, sustainable breast care nurse practice for the future will require clear policy development, exploration of appropriate and realistic funding mechanisms and organisational and professional support.

It is hoped that this summary report will be the catalyst for a service-wide discussion of the issues and a collaborative effort to ensure that the valuable breast care nurse resource is used to maximise the health outcomes of women with breast cancer.

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Appendix One

Reference Group and Steering Committee Membership

Reference Group

Ms Gina Akers, Cancer Support Nurse / Breast Care Nurse, The Alfred Hospital
Ms Melissa Billing, Breast Care Nurse Coordinator, Loddon-Mallee Breast Services Enhancement Program
Ms Andrea Cannon, Specialist Breast Care Nurse, Peter MacCallum Cancer Institute
Ms Suzi Grogan, Deputy Director, Cancer Information and Support Service, Anti-Cancer Council of Victoria
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Ms Mary Leahy, Nurse Unit Manager, Peter MacCallum Cancer Institute
Ms Gemma Sacco, Nurse Unit Manager, Breast Services, Monash Medical Centre
Ms Liz Stickland, Project Officer, Cancer and Clinical Services, Austin and Repatriation Medical Centre
Ms Kerry Shanahan, Breast Care Liaison Nurse, Royal Melbourne Hospital
Dr Ray Snyder, Medical Oncologist, St Vincent's Hospital, Melbourne
Associate Professor Kate White, Associate Professor of Cancer and Palliative Care, Edith Cowan University, Western Australia
Ms Tanya Wilson, Consumer Representative

Steering Committee

The Steering Committee was made up of the following staff from the Victorian Centre for Nursing Practice Research, School of Post Graduate Nursing, The University of Melbourne:

Professor Sanchia Aranda, Professor / Director of Cancer Nursing Research, Peter MacCallum Cancer Institute and The University of Melbourne
Dr Tracey Bucknell, Executive Director
Ms Robyn Faulkner, Research Fellow
Dr Linda Johnston, Associate Director
Ms Donna Milne, Research Fellow
Ms Felicity Osmond, Research Assistant