

IMPROVING SERVICES FOR WOMEN WITH BREAST CANCER BY ESTABLISHING THE ROLE OF BREAST CARE NURSE IN AUSTRALIA THROUGH A TERTIARY BASED DISTANCE EDUCATION PROGRAM

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Abstract

The Anti-Cancer Council of Victoria Cancer Information and Support Service (CISS) responds to over 36,000 calls per year. In 1999 20,000 calls were concerning female breast cancer. In the same period, there were three hundred women matched with a trained Breast Cancer Support Service Volunteer, 218 Cancer Support Groups and 39 Breast Cancer Support Groups were coordinated by this service. CISS is not only a means of disseminating information, it also has a finger on the pulse of the cancer community and can provide information regarding gaps in service.

An evaluation of Breast Cancer Support Service (BCSS) recommended that Breast Cancer Support Service (BCSS) nurses should increase their knowledge of breast cancer treatment and management throughout the whole continuum from diagnosis to death. This would enable the nurse to become a vital member of a multi-disciplinary team and a resource to women experiencing breast cancer, at any stage in her journey.

Acting upon these recommendations, CISS, in conjunction with La Trobe University, designed

and developed the first national, tertiary level training program for Breast Care Nurses. We recognise that well educated Breast Care Nurses can provide essential support and information to empower a woman with breast cancer to participate in treatment decisions and take control over her health and her life. The Breast Cancer Distance Education program has graduates from all states in Australia, New Zealand and South East Asia. The education program has been accredited with the Royal College of Nursing and has also been positively evaluated by the Centre for Behavioural Research in Cancer, who found that students rated the course highly and planned to change their nursing practice as a result of doing the course. Breast Care Nurses accredited with the Anti-Cancer Council of Victoria use accurate and up to date knowledge, advanced communication skills, and refer to other members of the multidisciplinary team to ensure that women with breast cancer receive the individualised support and the continuity of care they deserve.

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Author description:

Amanda Hordern

Amanda Hordern developed and coordinates the Breast Cancer Distance Education Program, a collaborative course run by Anti-Cancer Council of Victoria and La Trobe University. This tertiary-based education program for Breast Care Nurses is the first of its kind in Australia.

Amanda has in consultation with Breast Care Nurses and consumers, developed an ongoing educational framework for Australian BCNs to ensure that they maintain high standards of care. Consequently she plays a key role in promoting the role of the accredited Breast Care Nurse across Australia. She is also the Nurse Educator for the Cancer Information Service and a Nurse Counsellor at the Anti-Cancer Council of Victoria.

Doreen Akkerman

Doreen Akkerman, is the Director of the Cancer Information and Support Service (CISS) at the Anti-Cancer Council of Victoria. CISS includes a Cancer Helpline, Breast Cancer Support Service, Breast Cancer Nurse Distance Education Program, Cancer Support Groups Program, Welfare Grants, No Interest Loans Programs and an Outside Speakers' Bureau.

She developed the Australian model for Cancer Information Services, together with the comprehensive database which is used both nationally and internationally. Author of many published articles and reports regarding communication, development and maintenance of health information services.

Doreen currently serves as President of the International Cancer Information Services Group and Vice-President of the Victorian Association of Telephone Support Services.

**Key words: Breast Care Nurse - nurse education – accreditation –
credentialling – support - information needs .**

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Recent literature has highlighted the emergence of the specialist Breast Care Nurse (BCN) who is an integral member of the specialist breast care team (1, 2, 3, 4, 5). Concomitantly, an evaluation of the Breast Cancer Support Service (BCSS), a

unit within the Anti-Cancer Council of Victoria, Australia recommended that BCSS nurses should increase their knowledge of breast cancer treatment and management throughout the whole continuum from diagnosis to death (6). This would enable the nurse to become a vital member of a multi-disciplinary team and a resource to women experiencing breast cancer, at any stage in her journey. Acting upon these recommendations, the Anti-Cancer Council of Victoria, in conjunction with La Trobe University, designed and developed the first national, tertiary level training program for Breast Care Nurses (7).

How the Breast Care Nurse evolved in Australia – a brief history

Prior to this, for the past twenty-five years Breast Cancer Support Service nurses had attended a one day training program at the Anti-Cancer Council of Victoria to assist them to provide both information and support to women with breast cancer across Australia. In addition, two or three

training/clinical update sessions were offered throughout the year and it was up to each BCSS nurse to attend. Time, distance and work commitments often made it difficult for many nurses to attend the training sessions.

Over time it became apparent that there was considerable disparity in the information and support provided by the Breast Cancer Support Service nurses to women with breast cancer.

Developing an accredited Breast Care Nurse Education Program for Australian Nurses

In 1997 the Breast Cancer Distance Education Program replaced traditional training days for BCSS nurses. Since then, each nurse who now successfully completes the education program assessment requirements graduates as a BCN accredited with the Anti-Cancer Council of Victoria. Course accreditation requirements also include documented evidence of a clinical placement with an accredited BCN, a trained BCSS volunteer, or a Cancer Council. This credentialling process ensures that the BCN has met the designated practice standards of the course as determined by the Anti-Cancer Council of Victoria.

The Royal College of Nursing (Australia) has accredited the course until the year 2003.

Credentialling is one way to promote a national standard in a specialist area of clinical practice (8). An educational program such as this is one way of assuring the consumer, health professionals and the general public that information, support and referral from an accredited BCN is accurate, up-to-date and founded on research based evidence.

There are over 250 accredited Breast Care Nurses across Australia as well as a growing number of international Breast Care Nurses who are accredited with the Anti-Cancer Council of

Victoria. The Breast Cancer Distance Education Program can be taken as a single subject, or as a postgraduate diploma elective, in the Postgraduate Diploma of Advanced Nursing (PDAN) offered by the School of Nursing, La Trobe University. Successful students may also apply for credit at other universities or complete the Breast Cancer subject as part of other related Graduate Diploma and Master of Nursing university courses.

Defining the role of the Breast Care Nurse

Throughout the process of the development of the BCN education program, the role of the BCN has been defined and published in Australia where a detailed position description for the BCN is outlined in appendix 1 (9). Through defining the role of the BCN at a national level, plus implementing the development of standards of BCN practice, together with a collaborative approach within the multidisciplinary breast care team, optimal efficiency for the consumer can be achieved (1).

At an international level there are frequent references made to the BCN yet the role, training, clinical or practice setting and prerequisites of the BCN remain fragmented and vary enormously (10). In the USA, nurses who are recognised as experts within a defined area of knowledge and practice are required to have a Masters Degree or Doctorate in nursing (1). Yet there is no emphasis on combining clinical and practical skills for specialist nurses at these academic levels. In the UK the specialist nurse must undertake post graduate education combined with at least five years as a senior nurse in the wards or in the community (11).

Evaluation of the Breast Cancer Distance Education Program

The Breast Cancer Distance Education program has been positively evaluated by the Centre for Behavioural Research in Cancer (12) which found that students rated the course highly and many planned to change their nursing practice as a result of doing the education program.

Students expressed that they had learned most new skills in addressing psychosocial issues and symptom management. Interestingly, those students experiencing least confidence in providing support to women with breast cancer beforehand, experienced and maintained the greatest increase in confidence in carrying out Breast Care Nurse tasks after completing the course (12).

The most frequently cited changes following completion of the education program, related to improved communication skills with patients and their family, staff at outpatient clinics, breast cancer volunteers. Overall, students left the education program with a desire to implement their newly learned skills and at the 3 month follow up, 75% reported changes to their nursing practice as a result of completing the education program (12). The skills acquired from the Breast Cancer Distance Education Program aim to give specialist Breast Care Nurses the voice and recognition they require to competently care for women with breast cancer.

Key components of the Breast Cancer Distance Education Program:

The provision of psychological support to the woman with breast cancer

Providing individualised support to a woman with breast cancer is complex and health professionals often make inappropriate assumptions about the type of support or information women require throughout the disease process (13).

Many women affected by breast cancer feel that having breast cancer results in a distinct sense of “separateness” - irrespective of whether they have a supportive group of friends or a community

network. This may be due to the reactions of significant others who are often fearful and negative, forcing a woman with breast cancer to pretend that everything is back to “normal” (17). When a woman has to cope with feelings of isolation and lack of support there is little wonder that up to 42% of women remain anxious and clinically depressed following a breast cancer diagnosis (18).

Providing ongoing support is part of the role of the Breast Care Nurse

In Australia, the emergence of the accredited Breast Care Nurse (BCN) is having a positive impact on the overall support and information that women with breast cancer receive along the breast cancer continuum (5). The role of the Breast Care Nurse is multi-dimensional and is seen to be one of the most vital links a health professional can offer (19). The primary role of the BCN is to provide the woman with breast cancer, her family and carers with adequate support as well as the information and referral within a multidisciplinary framework throughout her breast cancer journey (4).

What impact is the provision of psychological support by the BCN having on the consumer?

It has been difficult for researchers to quantify the impact of the role of a BCN on the psychological and physical outcomes of a patient. However, researchers agree that, when adequate support and information are given to a woman with breast cancer, this can help reduce the harmful effects of stress she may experience and perhaps even contribute to a more satisfying, longer life (7). Poole (3) suggests that positive psychological outcomes for the patient are when the BCN is regarded as an educator, consultant, researcher, clinician and leader. It is vital that this nursing role is performed by an accredited BCN who has been educated to provide

reliable information and emotional support in a confirming relationship so that the patient can participate in treatment decisions and gain a sense of control over her situation (2, 5, 7).

It is interesting to compare the opinions of both nurses and patients when it comes to the issue of providing support to a woman and her carers following a breast cancer diagnosis. Few studies have been conducted to compare these two different points of view. Suominen, Leino-Kilpi and Laippala (13) found that nurses base the care they give women with breast cancer on their own assumptions of what type of support the woman may require. Thus it is exciting to note that, in Australia, the National Breast Cancer Centre (NBCC) is currently researching the role of the BCN in both rural and metropolitan settings. In particular the project aims to explore the notion of support and the informational needs of women with breast cancer in Australia (20).

Accredited Breast Care Nurses are in the position to provide individualised support to the consumer

When consumers and nurses disagree on the important forms of support, underlying issues need to be explored. Nurses completing the Breast Cancer Distance Education program are asked to reflect on the meaning of 'support' and then to explore what the concept means to both a nurse and the consumer - and finally to elicit what a consumer's expectations for support are at each stage of her illness.

Key contact schedule of support

It is imperative that women with breast cancer are provided with ongoing psychological support at a time when they often feel a sense of isolation and are very vulnerable. Consultation with accredited BCNs and consumers has assisted the development of recommendations for a *key*

contact schedule of support for health professionals. This would require the Breast Care Nurse to play a key role in the provision of psychological support at diagnosis, pre and post-operatively, then at one, three, six and twelve months post diagnosis. This supportive framework would be further enhanced by telephone contact when necessary.

Fortunately, the development of the Breast Cancer Distance Education program has challenged BCNs to not only question the type of support they offer all people affected by a breast cancer diagnosis but also to feel more confident about both their communication skills and their decision to refer patients on to other sources of support when the patient's needs exceed those of the role of the BCN (12).

Where are Breast Care Nurses located?

The difficulty in defining the BCN role may originate from the wide variety of positions Breast Care Nurses occupy in the Australian health system, working with women in pre-diagnostic to advanced breast cancer and palliative care centres and, more recently, in the area of genetic testing. A large network of BCNs provides service across Australia in the following locations:

- Public and private hospitals both rural and metropolitan
- Private medical practices
- District Nursing Centres
- Hospices and palliative care units
- Country District Nursing Services

- Other agencies eg: Breast Screen, Community Health Centres, and Familial Cancer Clinics.

Many accredited Breast Care Nurses undertake the role concurrently with their oncology, palliative care or community nurse positions. They are allocated to care for women with breast cancer as part of their case load for the day, often following up with support, written information, the matching of a trained BCSS volunteer or displaying a prosthesis kit when applicable.

In Australia, there is a growing recognition of the vital role which accredited BCNs play in supporting breast surgeons, oncologists, radiologists and other members of the interdisciplinary team (5). Recently, BCN positions have been created because members of the medical profession have sought the presence of an accredited Breast Care Nurse in their practice. These Breast Care Nurses conduct pre-admission clinics and provide support to the woman for as long as she requires it.

Support offered by the Anti-Cancer Council of Victoria to assist accredited Breast Care Nurses to maintain their educational status across Australia

To maintain their accredited status accredited BCNs must attend a minimum of 12 hours breast cancer related education per year . BCN attendances are logged onto a central database at the Anti-Cancer Council of Victoria. More recently, accredited Breast Care Nurses have elected to maintain a journal/log book in order to record these educational hours.

Debriefing/clinical update sessions for Breast Care Nurses

Debriefing/clinical updates are held monthly and are open to all nurses working in, or having an interest in, the area of breast cancer. Each session lasts 1.5 hours and is facilitated by the coordinator of the Breast Cancer Distance Education program. Breast Care Nurses determine the topics for the clinical updates which precede the debriefing and general discussion. Participants are asked to ensure that what is said within a session remains confidential so that participants are encouraged to seek support about any concerns in their clinical practice.

Some of the issues raised in these sessions include the development of clinical pathways or standards of best practice and collaborating to develop a Breast Care Nurse brochure. Twice a year the clinical updates are expanded to become a Breast Cancer Forum. A summary of the topics covered by the breast cancer experts is published in the Breast Cancer Support Service newsletter and distributed to all accredited Breast Care Nurses and to many clinicians across Australia.

Inaugural Breast Care Nurse Conference, Australia

In 1999, the Anti-Cancer Council of Victoria, Peter MacCallum Cancer Institute, University of Melbourne, Department of Surgery, Royal Australasian College of Surgeons, Victorian State Committee and St Vincent's Hospital collaboratively conducted the inaugural National BCN conference. The 1999 conference hosted in Melbourne was a huge success and will be hosted by different states of Australia on a bi-yearly basis. Every second conference being held in Victoria in conjunction with the Breast Cancer Surgical Update Conference. Meanwhile the ACCV has played a key role in the planning and development of a Breast Care Nurse Society through the Royal College of Nursing Australia. They continue to recruit financial sponsorship from

companies to be able to offer scholarships to successful BCN applicants who seek the recognition and professional endorsement the Breast Cancer Distance Education program offers.

Conclusion

A breast cancer diagnosis can be the beginning of a very traumatic, anxiety provoking experience in a woman's life. Many women feel quite isolated as they embark on their breast cancer journey because they do not wish to burden friends or family with their private fears or concerns. Obtaining up-to-date information and support from a BCN who is well educated in the area of breast cancer treatment and management is a powerful way a woman can gain control over the way she makes informed decisions. Breast Care Nurses accredited with the Anti-Cancer Council of Victoria but placed in all states of Australia, play a vital role in providing information and support to all who are affected by breast cancer. Consequently, it is important for all women to not only have access to an accredited Breast Care Nurse but to demand that their BCNs meet national education and clinical practice standards. This will mean that the BCN no matter where s/he is located in a rural outback or metropolitan area can provide the individualised support and the continuity of care women deserve.

Appendix 1

Authors : Doreen Akkerman & Amanda Hordern (9), Anti-Cancer Council of Victoria, Australia.

Position Description

TITLE: Accredited Breast Care Nurse

REPORTS TO: Employer plus Breast Cancer Distance Education Coordinator, Anti-Cancer Council of Victoria.

Executive Supervisor : Director Cancer Information and Support Service

QUALIFICATIONS/EXPERIENCE

Division 1 Registered Nurse working in the area of breast cancer.

Successful completion of the Anti-Cancer Council of Victoria/ La Trobe University Breast Cancer Distance Education program.

Evidence of post registration study is required (preferably to degree/post graduate level).

ESSENTIAL SKILLS

- A commitment to providing and maintaining a quality service
- Advanced communication skills

- Advocacy skills
- The ability to develop, implement and evaluate professional education programs

DESIRABLE SKILLS

- Second language
- Public speaking skills
- Ability to prepare and present reports clearly, both written and verbal

PERSONAL ATTRIBUTES

- Friendly manner
- Open communicator
- Team worker
- Excellent listener

AIM:

To use accurate and up-to-date knowledge as well as advanced communication skills, and to refer to other members of the multidisciplinary team ensuring that women with breast cancer receive the individualised support and the continuity of care they deserve.

POSITION SUMMARY

- Provide up-to-date information, support, linkage and referral by telephone or personal visit to women with breast cancer, throughout the continuum of their illness.
- To liaise effectively within the multidisciplinary team throughout all stages of the patient's care.
- To maintain the accredited BCN status and, as part of the Breast Cancer Support Service team, to abide by the Code of Ethics and Philosophy of the service.
- To receive referrals from clinicians, hospital personnel, Cancer Information and Support Service, other Breast Care Nurses in hospitals and community nursing agencies and, if required, co-ordinate BCSS volunteer patient-to-patient visits in hospitals and at home.

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Goals of Breast Care Nurse and Responsibilities

1. Keep up-to-date with evidence based information and resources in all areas of breast cancer through participation in:
 - A minimum 12 hours per year of breast cancer related education for all BCNs including metropolitan, rural, interstate and international accredited Breast Care Nurses.
 - A log book or journal must record your attendance at each of these sessions.
 - All interstate accredited Breast Care Nurses have been invited to participate in a bi-annual teleconference to assist you in maintaining information about the treatment and management

of breast cancer - (dates will be published in the BCSS newsletter at the beginning of each year).

2. Through professional commitment, provide specialised information, counselling, advocacy and support regarding breast cancer by personal visits either pre-operatively or post-operatively, maintaining a continuum of care for as long as the woman needs.

3. Provide the opportunity for women to access and discuss any issues related to breast cancer, including all aspects of diagnosis, treatment, recurrence and advanced disease, discharge and death.

4. Recognise individual limitations of the BCN role and refer to appropriate support throughout the continuum of care eg - Inform women of the following support services available through the Anti-Cancer Council of Victoria and local community: Cancer Information and Support Service/BCSS, support groups, palliative care services, District Nursing Services, community health centres, Living With Cancer Programs, National Breast Screen Centres etc.

5. Promote and co-ordinate BCSS volunteer visits for patients with breast cancer and provide linkage with the Breast Cancer Support Service staff.

6. Establish, develop and maintain a professional relationship with hospital and community contacts in order to promote and enhance the Breast Cancer Support Service for women with breast cancer and other health professionals.

7. Provide printed information on breast cancer and related issues as appropriate.

8. If appropriate, provide an opportunity to view a prosthesis display kit and also to provide information regarding temporary prosthesis, bras, swimwear and retail outlets.
9. Take responsibility for the maintenance of the breast prosthesis display kit at the workplace and contact Cancer Information and Support Service staff if there are any problems.
10. Complete and forward on to the Breast Cancer Support Service the patient profile card on each patient contact in order to contribute to a database of information designed to increase and enhance services to women with breast cancer.
11. Keep up-to-date on and provide information about referral procedures and any source of financial assistance available, ie. Anti-Cancer Council of Victoria Welfare Grant Program and No Interest Loan Scheme, private health fund, PADP, Veterans Affairs and hospital entitlements - including referral procedures.
12. Public speaking, training and resource development:-Within Anti-Cancer Council of Victoria guidelines, conduct appropriate training and educational sessions regarding breast cancer and provide resource materials for professional and community groups.

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