

Establishing an evidence base for the specialist breast nurse: A model for Australian breast cancer care

BARBARA LIEBERT, MICHAEL PARLE, KATE WHITE,
& ALAN RODGER

Barbara Liebert was the Specialist Breast Nurse study co-ordinator and Michael Parle was the Behavioural Scientist, NHMRC National Breast Cancer Centre, Sydney. Kate White is a Associate Professor, Cancer Palliative Care Nursing, Edith Cowan University W.A.

Alan Rodgers is Professor and Director, William Buckland Radiotherapy Centre, Alfred Hospital, Melbourne.

Abstract

The unmet needs of women with breast cancer have been extensively documented. In the United Kingdom, the introduction of the specialist breast nurse (SBN) role has been one strategy to improve the psychological wellbeing of women. This paper describes a SBN model of care and clinical pathway for Australian treatment settings, developed from systematic reviews of research and clinical practice guidelines for the treatment and psychosocial care of women with breast cancer. The model acknowledges the SBN as an integral member of the multi-disciplinary team with a key role to meet the emotional and informational needs of women diagnosed with breast cancer from the time of diagnosis through to follow up after treatment.

Key words: breast cancer, specialist breast nurse, evidence-based, clinical practice guidelines, clinical pathway, psychosocial support

Introduction

The specialist breast nurse (SBN) is recognised internationally as an important member of the multi-disciplinary team in the supportive care of women with breast cancer (Thomson, 1996). To date, there has been a lag in the development of these positions in Australia despite breast cancer being the most commonly diagnosed cancer and the leading cause of death from cancer in Australian women (Australian Institute of Health and Welfare, 1998). Moreover, there is evidence that many women's needs are not met during treatment for breast cancer in Australian treatment settings, particularly in regard to accessing sufficient information and supportive care, and receiving continuity of care (House of Representatives, 1995).

In response to community concern, the House of Representatives Standing Committee on Community Affairs conducted an inquiry into the Treatment and Management of Women with Breast Cancer in 1994. A total of 192 submissions from health professionals, women and their families on the management and treatment of breast cancer were received. Many women reported an inability to access adequate information, and considered that they rarely received their required level or frequency of communication with members of their treatment team. Despite the high incidence of serious psychological morbidity in breast cancer patients (Kissane et al, 1998), practical and psychosocial counselling and support were reported to be seldom offered. These submissions highlighted the need for a systematic approach to the provision of supportive care for women with breast cancer.

Specialist breast nurses

A recommendation that emerged from the inquiry was the need for more effective co-ordination of supportive care and counselling services, provided from within the multidisciplinary team.

“When a woman is being treated for breast cancer, there is a real and continuing need for her to be able to communicate freely and frequently with those treating her. The required level and frequency of communication, unfortunately, is rarely available, leaving some women dissatisfied with the advice they have received and feeling that they have not been given enough time and attention.” (House of Representatives, 1995 p 20)

The report also acknowledged the SBN, introduced previously in the UK, as one strategy for providing greater continuity of care and psychosocial support. SBNs are nurses with training and expertise in the management and treatment of breast cancer patients (MacMillan Cancer Relief, 1995). The emergence of SBN positions in the United Kingdom (UK) since the 1970s has become well established as good practice in the management of women with breast cancer (Jary & Franklin, 1996). The SBN sees women at diagnosis and during the course of treatment to provide information, co-ordinate supportive care and to screen for the development of anxiety and depression (Jary & Franklin, 1996).

The evolution of the SBN as a nurse with specialist skills and expertise related to breast cancer is supported by the recognition of the clinical nurse specialist (CNS) role within health care. Originating in North America, the CNS has been widely adopted into all areas of health care (Hunt, 1999). The CNS position has developed in line with the expansion of knowledge, expertise and technology in health care, and is recognised as delineating an experienced clinician, with advanced expertise and skills. As the provision of health care increased in complexity, a growing number of specialties and sub-specialties has evolved in both medicine and nursing (Castledine, 1983, 1994). While the CNS role varies and is dependant on the clinical setting, core attributes of this position are clinical expert, resource consultant, educator, change agent, researcher and advocate (Miller, 1995). While there remains confusion about a clear role description for CNSs, implicit in the role is the need for specialist knowledge developed from extensive clinical experience and formal education (Hamric, 1992). More recently, the CNS has been seen as having a pivotal role in the development of evidenced-based clinical practice (Hamric & Spross, 1989).

The role of the SBN has been extensively evaluated in both randomised controlled trials (RCTs) and descriptive studies. There is evidence from RCTs 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, 1996; Watson et al, 1988). SBNs also increase early detection and referral of women with psychological morbidity for professional counselling (Maguire 1980; 83; 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 when compared to women who did not have access to such a nurse (Clacey et al, 1988). Thomson (1996) contends that this makes breast care nursing one of the more soundly research-based of the many specialist nursing developments of recent years.

Despite the clear, demonstrated benefits of SBN positions in research trials, there remains an absence of an explicit role definition for practising nurses (Poole, 1996). The application of the best available research as a framework for clinical practice has been a relatively new approach within the nursing domain (Middleton & Lumby 1998). The use of information derived from quality research to improve the effectiveness of nursing care and reduce variability in practice has been more commonly applied to discrete (or procedural) nursing practices (Lockwood, 1999) rather than in the development of clinical pathways for specialist nurses.

Current breast nurse practice in Australia

The lack of a clear role definition is also of concern in Australia. While there is growing interest in the concept of SBNs in Australia, there has been no standardised approach to the provision of SBNs in Australia or the care they provide. There are a number of nurses who practice as a SBN as a variable percentage of their work (Neale, 1997). There is considerable range in the knowledge and skills of practising breast nurses, yet no agreed standard of practice. In some cases, the breast nurse is a volunteer while others have substantial ward duties other than the provision of information and supportive care (Webb & Koch, 1997). Increasingly recognised is that variability in clinical management is most commonly attributed to a lack of familiarity with options, guidelines and standards (Awad et al, 1999).

In an attempt to define commonalities of the current role of breast nurses in Australia, White (1998) surveyed 16 breast nurses who spent more than 70% of their work time caring for patients with breast disease. The breast nurses were asked to identify descriptors and rank their importance in describing their role. Consistent with findings overseas, the breast nurses perceived their role as primarily providing psychosocial support for patients with breast cancer, although some nurses perceived their role to include all breast diseases. However, unlike the UK model, only 56% of the nurses surveyed attributed importance to co-ordinating the 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.

Australian women also report the care and availability of breast nurses to be highly variable. In a recent national survey of 545 women diagnosed with early breast cancer (NBCC, 2000a), 46% of women reported no access to a breast nurse and for those women that did have access to a breast nurse, few experienced the care as outlined in the RCTs described above. For the purpose of the survey, a breast nurse was defined as a nurse who specialises in breast cancer and gives information and support to women throughout diagnosis, treatment and follow up. Only 25% of women reported seeing a breast nurse on more than one occasion and just 14% had repeated contact with the breast nurse from the time of diagnosis to the post-operative period. Women were most commonly seen by the breast nurse while they were inpatients (30%) or within 2 months of surgery (22%). Fewer women were seen at diagnosis (14%) or 2 to 4 months after surgery (12%).

Women in the above study were also surveyed about their access to information and support. Women who were seen by the breast nurse on three or more occasions were better informed about treatment side effects ($\chi^2=4.7$, $P<.05$), follow up after treatment ($\chi^2=4.5$, $P<.05$) and clinical trials ($\chi^2=8.7$, $P<.01$) than women who had no contact with a breast nurse. They were also more satisfied with the level of support that they ($\chi^2=8.5$, $P<.0005$) and their family received ($\chi^2=11.4$, $P<.0001$).

These findings suggests that positions that more closely approximate the care provided by SBNs as outlined in RCTs, provides better outcomes for women and their families. There is therefore, a need to identify practices that are effective and can be implemented in routine clinical settings.

An evidence-based model of care for SBNs

Evidence-based practice involves the use of the best evidence available for making clinical decisions about patient care (McPheeters & Lohr, 1999). Applied in a specialty area, guidelines from sound research can be comprehensively applied by way of a clinical pathway for practising clinicians. This not only ensures a standardised approach to care but promotes a higher level of excellence and quality care (Awad et al, 1999) and may provide a useful framework for consideration in a medicolegal context (Pelly et al 1999).

The National Breast Cancer Centre (NBCC) sought to use evidence based guidelines to develop and trial a SBN model of care for Australian treatment settings (NBCC, 2000b). The SBN model of care was formulated from evidence-based recommendations of two management guidelines: *The Clinical practice guidelines for the management of early breast cancer* (1995), and the NBCC's *draft clinical practice guidelines for the management of advanced breast cancer* (1997), and a draft version of the National Breast Cancer Centre's *Psychosocial clinical practice guidelines for providing information, support and counselling to women with breast cancer* (1999) (hereafter referred to as the Psychosocial Guidelines).

In addition to specific recommendations, the guidelines underscore the importance of continuity of care, the collaborative role of the multidisciplinary team, and an awareness of psychosocial, cultural and spiritual issues in the care of women with breast cancer. Recommendations for clinicians are based on comprehensive reviews of both published and unpublished literature on the clinical and psychosocial aspects of breast cancer and assigns a rating of the quality of the evidence consistent with the NHMRC's Standing Committee on Quality of Care and Health Outcomes (Table 1). For instance, separate reviews have examined psychosocial support, provided by members of the treatment team and specialist providers (Bourke and Kissane, 1998). *The Management guidelines* aim to provide the best available evidence on which decisions can be made by women and treatment team members. *The Psychosocial guidelines* address the psychosocial aspects of breast cancer and thus aims to equip all members of the multidisciplinary team with a sound evidence base for providing

psychological support. However, given that the guidelines were developed for use by all members of the treatment team, members of the multidisciplinary team must extrapolate the *Guidelines'* clinical relevance for their particular profession.

Table 1: Rating of Evidence

Level I	evidence is obtained from a systematic review of all relevant randomised controlled trials, usually found in meta-analyses
Level II	evidence is obtained from at least one properly designed randomised controlled 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 IV a	evidence is obtained from descriptive studies of provider practices, patient behaviours, knowledge, or attitudes or a systematic review of the descriptive studies
Level IV b	represents the opinions of respected authorities based on clinical experience or reports of expert committees.

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

Reprinted from National Health and Medical Research Council 1995, *Clinical practice guidelines: The management of early breast cancer*

The proposed SBN model of care aims, therefore, to translate findings from international studies which have evaluated SBN positions and recommendations from evidence-based guidelines into a framework that is clinically relevant for practising breast nurses. The result is the formation of a clinical pathway, which will enable a more structured approach to the provision of clinical and supportive care by SBNs, and convey role clarity within the multidisciplinary team context. Importantly, it marks a significant development in nursing, through the application of an evidence-based approach to the provision of supportive care by SBNs.

The SBN clinical pathway

Following the clinical pathway, the SBN complements the roles of others in the treatment team by reinforcing key information which has been provided to a woman diagnosed with breast cancer and by co-ordinating her supportive care. Appendix 1 provides a summary of the clinical pathway. The pathway guides the SBNs in their assessment and response to the women's needs for information, practical assistance, emotional and psychological support and awareness of cultural and spiritual beliefs that may affect a woman's response to breast cancer and the proposed treatment options.

To assist the SBN implement the clinical pathway, a consultation checklist was developed (NBCC 2000b). The checklist included core points to cover in the SBNs assessment, on the basis of recommendations from the clinical practice guidelines. The evidence and rationale for the clinical pathway and checklists are described below.

Discussing treatment options

Women report a desire to be well informed about their diagnosis and treatment options and there is Level I evidence indicating that adequate information is related to increased psychological well-being (NBCC, 1999). The Psychosocial Guidelines recommend that clinicians inquire about factors important to women and which may influence treatment decisions, and provide alternatives for expanding treatment options. The SBN is well suited to exploring a woman's specific concerns in more detail, and to reinforcing information provided by other health professionals. Furthermore, the *Psychosocial Guidelines* provide a number of strategies for improving clinician's interactional skills that the SBN can utilise. These include conveying support, providing clear information, avoiding medical jargon, promoting questions and offering to tape key consultations so that the woman has a record of important information that was provided.

Provide information about practical issues

Practical issues facing a woman being treated for breast cancer can include the cost of travel and treatment, time away from home and the need for travel and accommodation during treatment. These practical considerations

may influence a woman's treatment decisions and her wellbeing (level IVa; IVb NBCC, 1999). The Psychosocial Guidelines make recommendations for dealing with practical issues that the SBN is well suited to implement. For instance the SBN is able to include an assessment of practical issues relevant to each woman such as the need for child-minding, access to special clothing, wigs, and prostheses, and information on the cost of treatment and eligibility for financial rebates.

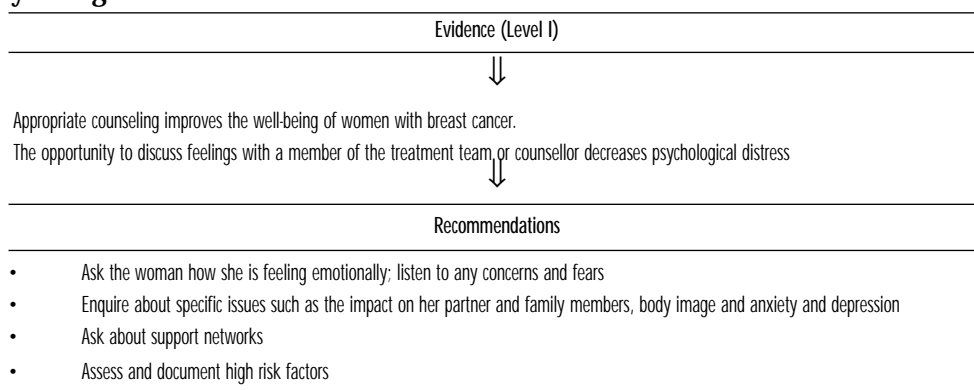
Preparing women psychologically for potentially threatening procedures

Although the prospect of surgery for breast cancer can cause high levels of psychological distress (Bourke & Kissane, 1998), addressing a woman's specific concerns with appropriate procedural information including practical details about what will happen before, during and after a procedure can significantly reduce emotional distress (level I, NBCC 1999). The SBN can support the surgeon's role by being available to further discuss aspects of the procedure if required. Support from a SBN at this time has been shown to be effective (level II NBCC 1999). Additionally, the Psychosocial Guidelines make recommendations about strategies to reduce a woman's level of anxiety including encouraging the woman to discuss her concerns and fears as well as her coping strategies. Again, the SBN has a valuable role to play in implementing these recommendations and offering education about additional exercises and resources.

Providing support and counselling

There is level II evidence indicating that supportive care from a SBN facilitates early recognition of social support needs and decreases psychosocial distress (NBCC, 1999). There is also level III evidence suggesting that women who are given the opportunity to discuss their family and support networks with a member of the treatment team have better emotional adjustment (NBCC, 1999). Continuity of care, intrinsic to the SBN pathway, provides women with greater accessibility for discussing sensitive issues such as interpersonal problems. SBNs have previously been found to facilitate the early detection and referral of women with psychological difficulties (level II; NBCC, 1999). The Psychosocial Guidelines provide further specific recommendations to assist the SBN assess psychological, psychosexual, physical and interpersonal issues any individual woman may be facing as a result of her breast cancer diagnosis (Figure 1).

Figure 1: recommendations from evidence-based guidelines in providing psychological care



Adapted from 'Psychosocial clinical practice guidelines: providing information, support and counselling to women with breast cancer'

Discussing cultural, religious and spiritual issues

A woman from a culturally diverse background may have a cultural sensitivity that requires specific information, services or other factors that the team need to consider in the woman's care. As the co-ordinator of supportive care, the SBN needs to take a leading role to understand the significance of a woman's cultural background and its impact on her expectation of care. The Psychosocial Guidelines make recommendations about ways to ensure women have access to adequate information and support services. These may include the use of interpreters, written information in a woman's own language and a thorough awareness of her cultural sensitivities.

Timing of consultations

The scheduling of consultations also concurs with an evidence-based approach. The model was operationalised in the '5 in 12' clinical pathway and comprised of five predetermined nurse-initiated consultations linked with key treatment phases including diagnosis, pre-operative, post-operative, and two follow-up appointments after discharge from hospital (NBCC 2000b). However, the model needs to retain enough flexibility for women to make additional appointments with the SBN at any stage during treatment, follow-up or after the designated 12-week intervention period. The evidence to support the timing of consultations is presented below.

Diagnosis

The model recommends the SBN be present when a woman receives her diagnosis of breast cancer, or at least is introduced to her within the following 48 hours. Level II evidence indicates that women who have had the opportunity for further discussion with a SBN who is present during the consultation when news of a diagnosis is given, experienced less psychological morbidity, increased understanding of breast cancer, remember information better and have enhanced perceptions of support (NBCC, 1999). Additionally, the presence of the SBN from the time of diagnosis emphasises the role of the SBN in providing continuity of care.

Pre-operative and post-operative consultations

Providing women with information about the procedure they are about to undergo can reduce their emotional distress and aid their psychological and physical recovery (level I; NBCC, 1999). Thus the main focus of the pre-operative consultation is to prepare the woman psychologically, for a potentially threatening procedure by providing adequate information about the surgical procedure and offering psychosocial support.

The implications of the surgical results, and their impact on prognosis and further treatment decisions, including participation in clinical trials, requires the woman to have access to new sources of information from the clinician and treatment team. Early discharge programs, in which a woman is discharged within 48-72 hours post-operatively often with a drain in situ, may introduce new issues such as support at home, post-operative recovery and its effect on role functioning. Importantly, women's ongoing access to information and support from the SBN throughout their treatment allows for the provision of information to be given in stages.

Follow-up consultations after discharge

Women with breast cancer continue to report a lack of continuity of care (level IVa; NBCC, 1999). By extending the intervention to include the commencement of adjuvant therapy, the SBN can continue to co-ordinate supportive care, provide information about the next stages of treatment and link the woman to new members of the multidisciplinary team accordingly.

Conclusion

The proposed SBN model of care is a timely example of how evidence-based guidelines can be implemented in clinical practice. In particular, the Psychosocial Guidelines have summarised the strongest evidence regarding the SBN's role and made recommendations that may be translated into the SBN's core activities. The Psychosocial Guidelines also have broader implications for all members of the multidisciplinary team. As the recommendations from the Clinical practice guidelines' summarise the evidence from international studies, the model promises to be relevant for most treatment settings. The model needs also to retain enough flexibility to be adapted to meet the requirements of a given treatment setting and be integrated successfully into the existing treatment team. As such, the model needs to be trialled in diverse treatment settings so that its feasibility can be evaluated. This will also provide an important blue print for testing how an evidence-based model for nursing practice works in a clinical setting.

References

- Australian Institute of Health and Welfare (AIHW), Australasian Association of Cancer Registries (AACR) and NHMRC National Breast Cancer Centre, 1998, 'Breast cancer survival in Australian women 1982-1994', *AIHW (Cancer Series No.9)*, Canberra
- Awad IA, Fayad P & Abdulrauf SI 1999, 'Protocols and critical pathways for stroke care', *Clinical Neurosurgery*, vol 45, pp 86-100
- Burke S & Kissane DW 1998, 'Psychosocial support for breast cancer patients provided by members of the treatment team. A summary of the literature 1976 - 1996', *NHMRC National Breast Cancer Centre*, Sydney
- Castledine G 1983, 'The nurse for the job', *Nursing Mirror* vol 19, p 43
- Castledine G 1994, 'Specialist and advanced nursing and the scope of practice', in G Hunt & P Wainwright (eds) *Expanding the Role of the Nurse*, Blackwell Science, Oxford.
- Clacey R, Thomas C & Pearson H, 1988, 'Does counselling by nurses for mastectomy patients work?', in M Watson, S Greer & C Thomas (Eds) *Psychosocial Oncology*, Pergamon, Oxford.
- Hamric AB 1989, 'History and overview of the CNS role', in AB Hamric & JA Spross (eds) *The Clinical Nurse Specialist in Theory and Practice* 2nd edn, WB Saunders, Philadelphia.
- Hamric AB 1992, 'Creating our future: challenges and opportunities for the clinical nurse specialist', *Oncology Nursing Forum*, vol 19, no 1, pp 11-15
- House of Representatives Standing Committee on Community Affairs, 1995, '*Report on the management and treatment of breast cancer in Australia*' Canberra: Australian Government Publishing Service.
- Hunt JA 1999, 'A specialist nurse: an identified professional role or personal agenda?', *Journal of Advanced Nursing*, vol 30, no 3, pp 704-712.
- Jary J & Franklin L 1996, 'The role of the specialist nurse in breast cancer', *Professional Nurse*, vol 11, no 10, pp 664-5
- 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 Australia*, vol 169, pp 192-96
- Lockwood C 1999, 'Consolidation of an evidence based approach to practice manual literature reviews', [Online], Available: <http://www.joannabriggs.edu.au/craig1.html> [Accessed 1999, Dec 28]
- Guidelines for the operation and management of a MacMillan Breast Care Nursing Service, 1995, *MacMillan Cancer Relief*, London.
- Maguire GP, Tait A, Brooke M, et al. 1980, 'Effect of counselling on the psychiatric morbidity associated with mastectomy', *British Medical Journal*, vol 281, pp 1454-6.
- Maguire P, Brooke M, Tait A, et al. 1983, 'Effect of counselling on physical disability and social recovery after mastectomy', *Clinical Oncology*, vol 9, pp 319-24.
- McArdle JMC, George WD, McArdle CS, et al. 1996, 'Psychological support for patients undergoing breast cancer surgery: a randomised study', *British Medical Journal*, vol 312, no 7034, pp 813-816
- McPheeters M & Lohr KN 1999, 'Evidence-based practice and nursing: commentary', *Outcomes Manag Nurs Pract*, vol 3, no 3, pp 99-101
- Middleton S & Lumby J 1998, 'Outcome evaluation in nursing in Australia, 1960-1980', *Australian Health Review*, vol 21, no 4, pp 72-9
- Miller S 1995, 'The clinical nurse specialist: a way forward?' *Journal of Advanced Nursing*, vol 22, pp 494-501
- National Breast Cancer Centre 1999, 'Psychosocial clinical practice guidelines for providing information, support and counselling to women with breast cancer', draft, *National Breast Cancer Centre*, Sydney.

- National Breast Cancer Centre 2000a, 'National consumer survey of the perceptions of care of women with breast cancer', *National Breast Cancer Centre*, Sydney.
- National Breast Cancer Centre 2000b, 'Specialist breast nurses: an evidence-based model for Australian practice', *National Breast Cancer Centre*, Sydney.
- National Health and Medical Research Council 1995, 'Clinical Practice Guidelines: The Management of Early Breast Cancer' *National Health and Medical Research Council*, Canberra, AGPS.
- NHMRC National Breast Cancer Centre 1998, 'Clinical Practice Guidelines for the Management of Advanced Breast Cancer', draft, *National Breast Cancer Centre*, Sydney
- Neale S 1997, 'Specialist breast nurses can help', *Breast News*, vol 4, no 2, p 7
- Pelly JE, Newby L, Tito F, et al. 1998, 'Clinical practice guidelines before the law: sword or shield', *Medical Journal Australia*, vol 169, no 21, pp 330-3
- Poole K 1996, 'The evolving role of the clinical nurse specialist within the comprehensive breast cancer centre', *Journal Clinical Nursing*, vol 5, no 6, pp 341-9
- Thomson L 1996, 'Continuity in care', *Primary health care*, Vol 6, no 9, p 8
- Watson M, Denton S, Baum M, et al. 1988, 'Counselling breast cancer patients: A specialist nurse service', *Counselling Psychology Quarterly*, vol 1, no 1, pp 25-34.
- Webb C & Koch T 1997, 'Women's experiences of non-invasive breast cancer: literature review and study report', *Journal of Advanced Nursing*, vol 25, pp 514-525
- White K, Wilkes L & Campbell A 1997, 'The role of the breast nurse: the Australian context', *Australian Catholic University*, North Sydney
- Wilkinson S, Maguire P & Tate A, 1988, 'Life after breast cancer', *Nursing Times*, vol 84, pp 34-7

