Research Article

Supportive care for women with breast cancer: Australian nurses’ perspective

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Abstract

A research project was undertaken to describe how the support needs of women who have had treatment for breast cancer were being met in New South Wales, Australia. Data were collected from both the women and the nurses who cared for them. The findings from the first part of the study examined the nurses’ perceptions of the women’s needs and how they as health professionals, fulfilled these needs. Analysis was both qualitative and quantitative. Seventy-eight nurses responded to a questionnaire and 15 were interviewed. The findings indicated that the nurses perceived information on disease process and physical aspects of the disease as essential to supporting the women with breast cancer. While they saw providing emotional support to the women as important the nurses themselves often lacked the time and skills to provide it.

Key words

Australia, breast cancer, nurse’s views, support, women.

INTRODUCTION

Support is seen as crucial to the care of women diagnosed with breast cancer (Feather & Wainstock, 1989; Northouse, 1989; Suominen, 1994; Suominen et al., 1995; Lugton, 1997). Cocker and Kidman (1995) report preliminary results showing that support affects survival rates in women with metastatic breast cancer. Support has been defined by a number of healthcare workers as including social/emotional (intimacy attachment, reassurance, relationships), informational (guidance and information) and instrumental/physical (direct care and services) aspects (Samarel & Fawcett, 1992; Rees et al., 1994; Suominen et al., 1995).

Nurses have a role to play in providing support to women with breast cancer (Anderson, 1989; Suominen, 1992; Suominen et al., 1995). Nursing intervention, focusing on emotional support has been shown to improve a woman’s sense of control during the period of diagnosis and primary treatment of stages I and II breast cancer (Palsson & Norberg, 1995). In a Finnish study, Suominen and Laippala (1993) found that nurses perceived their major supportive role as to provide information and ensure continuity of care (‘informing the woman about the next stage of care’) and comfort to the women. Studies have implied that family and friends are more supportive than nurses (Bullough, 1981; Anderson, 1989; Suominen et al., 1995) and that support in hospital from nurses and other health professionals in particular is almost non-existent (Feather & Wainstock, 1989; Suominen & Laippala, 1993).

It is not clear whether Australian women include nurses in their support network when they are diagnosed and treated for breast cancer. In a study in one state of Australia, New South Wales (NSW), we sought to explore the extent and type of support provided by nurses to women with breast cancer. The perspective of the women and nurses has been explicated. This paper describes the nurses’ perspective, gained from mailed survey questionnaires and interviews.

The aim of the questionnaire survey of nurses and subsequent interviews was to determine the nurses’
perceptions of the support needs of women with breast cancer and how the nurses managed these needs in their day to day practice. It is important to note that while the role of specialist breast care nurses is being developed in Australia, most women diagnosed with breast cancer will be cared for by nurses with varying and different levels of expertise.

**METHOD**

**The questionnaire**

A questionnaire developed by Suominen and Laippala (1993) was modified for the study in relation to the sequence of questions. It included closed and open-ended questions relating to the support needs of women with breast cancer. Demographic information on the age, clinical experience and education of the nurses was also elicited in the questionnaire.

**The participants**

A cross-sectional sample of 380 nurses in NSW was accessed through the NSW Oncology Nurses’ Group, Association of Palliative Care Nurses and wards with breast cancer patients in three major metropolitan hospitals (Liverpool Hospital, St Vincent’s Public Hospital, Mater Misericordiae Hospital) Sydney, New South Wales, Australia.

**Data collection**

The questionnaires and a return stamped address envelope were mailed to the participants through the regular postal mailout for the professional organizations. Participants in the three metropolitan hospitals were approached by a member of the research team who visited the specified clinical areas and explained the project. Questionnaires were left with a sealed envelope, and collected 3 weeks later.

**Interviews**

At the end of the questionnaire respondents were asked if they wished to be interviewed. Using a semi-structured format the researchers interviewed those nurses who volunteered in order to expand and enhance on the data gained from the questionnaire responses. Interviews were conducted at a time and location convenient to the participant and audiotaped.

**Data analysis**

Quantitative data from the questionnaire were entered into the SPSS computer package (SPSS Australasia Pty Ltd, Sydney, NSW, Australia) for the IBM computer. Frequencies of responses to questions were tallied, percentages calculated and tabulated.

Qualitative data from the questionnaire responses and the transcribed, audiotaped interviews were entered into the Ethnograph version 4.0 computer software (Scolari, Sage Publications Software, Thousand Oaks, CA, USA) (Siedel et al., 1995) to assist with sorting coded segments of text. The researchers coded the data in relation to the type and extent of support provided by the nurses to women with breast cancer. The most frequently recurring codes were tallied and tabulated. Following constant comparison of coded segments of text a description of the nurses’ perceptions of their supportive care for women with breast cancer was written.

**RESULTS**

**Respondents**

Seventy-four nurses (response rate 20%) returned completed questionnaires. This was a low response rate; therefore, the opinions can only be seen as general trends in the supportive care provided by nurses for women with breast cancer. Seventy-seven percent of the 78 nurses were specialist nurses with oncology/palliative care qualifications. Twenty-two nurses (30%) worked in community palliative care and 24 (33%) worked in oncology wards in hospitals. Of the remainder, 22 (30%) worked in generalist community care and five (1%) worked in a surgical ward. The median number of years caring for women with breast cancer was seven. While the response rate to the questionnaire was low, the demographics of the nurses highlights that they were experienced, highly qualified nurses whose role in the hospital or community setting was at the nurse specialist level. Fifteen nurses agreed to be interviewed, of whom 12 had oncology qualifications with five working in the community and 10 in a hospital setting.

**Supportive care**

From the analysis of the quantitative and qualitative data, the nurses’ perceptions of their support of the informational, physical, social and emotional needs of women with breast cancer can be described. As resonated by the nurses in the questionnaire and in interviews, the support of a woman with breast cancer cannot be prescriptive but is variable, individual and constantly changing:

It’s always a swing... it’s up and down... accepting the diagnosis and accepting the treatment, it always comes in waves for everybody
really . . . sometimes they are up, and that’s fine and then when they’re down you try and reassure them again . . . you’re not giving them guarantees.

**Informational needs**

The nurses saw providing information on various aspects of the woman’s journey with breast cancer as their most important role. The nurses used a variety of visual, written and verbal media to accommodate the individual needs of the women. They stressed that to be effective, information giving needed to be evaluated as to its amount and timing, and attuned to the emotional state of the woman, her literacy and English skills.

From the questionnaire responses in Table 1, 62 (84%) of the nurses reported that they provided support by giving the women information about the breast cancer disease process. They stated that this information should include classification of the cancer, prognosis and survival, treatment options and side effects of treatments. In particular, the nurses stressed that the woman with breast cancer had the right to be informed of treatment options, especially lumpectomy, mastectomy, radiotherapy, chemotherapy and alternative therapies. As one nurse voiced at interview:

> ... they want to know what the options are, they want to know what the possibility of the future is, they want to have a lot more involvement [in decision making].

As illustrated in the above quote the nurses felt that the women needed this knowledge in order to make informed decisions relating to treatment. However, in the rural community the timing of the discussion of these treatment options was often too late:

> ... they . . . [the women] . . . certainly in . . . [the country] . . . are more likely to have their surgery prior to seeing options . . . they seem to just have had the surgery when they come [to out-patients clinic].

The nurses also commented that in many cases when rural women were given options they often decided on the one which meant less time away from home, less financial difficulty and less travel.

Information on exercise of the arm on the affected side was seen as an essential supportive behavior by 65 (88%) of the questionnaire respondents (Table 1). At interview the nurses commented on the delegation of this responsibility to the physiotherapist. With long-term care of the arm most of the nurses gave information but they emphasized the need for a team approach with the physiotherapist and occupational therapist. Information on lymphedema care was seen

| Table 1. Respondents’ perceptions of their supportive care for women with breast cancer |
|---------------------------------|---------------------------------|---------------------------------|
| Supportive care                        | Provided No. (%) | Not sure No. (%) | Not provided No. (%) |
| **Information**                        |                  |                  |                        |
| Disease process                         | 62 (84)          | 8 (11)            | 4 (5)                  |
| Treatment options                        | 46 (62)          | 11 (15)           | 17 (23)                |
| Procedure details                        | 55 (74)          | 8 (11)            | 11 (15)                |
| External prosthesis                      | 48 (65)          | 10 (14)           | 16 (21)                |
| Financial benefits                        | 33 (45)          | 22 (30)           | 19 (25)                |
| Breast cancer support services            | 63 (85)          | 8 (11)            | 3 (4)                  |
| **Nursing assistance, information and education on** |                  |                  |                        |
| Day to day basic care                      | 48 (65)          | 9 (12)            | 17 (23)                |
| Exercise of the arm on the affected side  | 65 (88)          | 5 (7)             | 4 (5)                  |
| Long-term care of the arm                | 63 (85)          | 7 (10)            | 4 (5)                  |
| Surgical wound                           | 60 (81)          | 8 (11)            | 6 (8)                  |
| Optimal pain relief                      | 71 (96)          | 2 (3)             | 1 (1)                  |
| **Providing psychological support through** |                  |                  |                        |
| Counseling in relation to altered body image | 62 (84)          | 6 (8)             | 6 (8)                  |
| Listening and talking                     | 66 (90)          | 4 (5)             | 4 (5)                  |
| Allowing woman to express feelings        | 66 (90)          | 4 (5)             | 4 (5)                  |
| Offer help through a nursing presence    | 70 (95)          | 4 (5)             | 0                      |
| Treating the woman as an individual      | 66 (90)          | 4 (5)             | 4 (5)                  |
| Comfort and reassurance                   | 66 (90)          | 4 (5)             | 4 (5)                  |
as imperative for the woman’s ongoing self-care. As one nurse asserted:

How many . . . [of the women] . . . are truly told the possibility of lymphedema after the surgery, and when it happens what to do.

Over half of the nurses (65%) provided information to the women about external prosthesis, and 21% did not consider it part of their nursing role (Table 1). At interview the nurses suggested that many women did not know where and how to obtain a prosthesis nor about monies available to support this endeavor. For example, one nurse working in an out-patients clinic stated:

We often find that when the patients come here they haven’t had any of that sort of information at all. . . . In NSW the first one . . . [prosthesis] . . . is free. That’s a big help.

Community services and support, especially breast cancer support groups, were considered important elements of supportive care by 85% of questionnaire respondents (Table 1). At interview, the community nurses emphasized that hospital nurses were not always aware of the range of the supports and services available to women with breast cancer on discharge:

Where’s the relationship with their community support, where is, you know what is affecting this person’s health. Is it just the physical condition or is it more a financial problem, is there abuse, is there a problem with a neighbor . . . what’s impacting on this person’s wellbeing?

Many nurses reflected that in order to support the woman, nurses and other health professionals need to be better informed about these services so that referral is made easier than it is now.

**Physical needs**

As noted in Table 1 the nurses provided support on the physical aspects of care by providing information but they also assisted the woman with her day to day care if needed (65% of questionnaire respondents). They considered the provision of optimal pain relief essential in their supportive role (96% of questionnaire respondents). Over half of the nurses (81%) provided assistance and information for surgical wound care. However, one-third of the nurses did not perceive this aspect of care an important part of their role. At interview, the nurses emphasized that while the women were referred to community nurses for the care of wounds they often took on their own wound care because the community nurse could not visit at a set time. This was a problem in particular for elderly women:

They don’t like sitting there all day waiting, when’s this nurse going to come . . . particularly those that have experienced them previously, I find that they’re really reluctant to have community nurses in again. Not because of the service, or because of the nurses themselves, but because of the time frame.

**Social relationship and emotional needs**

Seventy-nine percent of nurses perceived that the woman’s relationship with her partner/spouse changed with the advent of breast cancer and that support was imperative. As expressed by one nurse:

They either seem to separate before they come to . . . [radiotherapy] . . . that’s happened quite a bit actually before they come for radiotherapy . . . they either seem to clear out, or they come closer and really support and come with the patients to the service for further treatment.

It was seen as important for the partner to know when the woman was ready for intimacy:

. . . It’s very difficult for the partner, because they’re just not sure whether they’re ready for sex, whether they want sex . . . .

and appreciate the woman’s hesitancy:

. . . but then if it comes down to any intimacy they hesitate.

While half the nurses viewed that breast cancer presented no difficulties for the woman at work, at interview some told a different story:

. . . a few ladies have actually been demoted . . . two have lost their jobs because they have had breast cancer . . . a few of them are given a fairly hard time by their colleagues, co-workers. Rather than being supported, it’s very surprising men and women either seem to pile the work on or are not supportive with the time that’s needed to come for treatment if they continue working.

The nurses expressed mixed opinions about the effect of breast cancer on the woman’s friendships. At
interview many of the nurses spoke of the social isolation of living with breast cancer and how friends often withdrew because they did not know how to support the woman or were frightened by the illness event:

They’re certainly affected I guess in a major way by withdrawal of friends, close friends who possibly don’t have an understanding of what’s going on and maybe have a fear about what’s going on . . .

Emotionally the nurses highlighted that the women’s reactions were variable. The main effects for the women related to self-image and body image:

And I still have a lady . . . she had a mastectomy two and a half years ago and she’s still not been able to look at herself, she wears prosthesis. She hasn’t been able to stand in front of the mirror yet and when she has a shower she just washes, but she never looks.

The nurses emphasized that the woman’s altered body image often impinged on her perception of herself in social relationships, especially with her partner. Contrary to this the nurses related how the partners were often not concerned:

And he supported her and was very encouraging and I had men say ‘look, I don’t care what she looks like, she’s worried about what she looks like and whatever, I don’t care’.

In order to cope with the emotional effects of breast cancer the nurses felt that the woman often developed a mask:

And quite often people feel that they have gotta put a front on, a mask because they’re fine and they don’t worry their family or anything. I think the emotions have to be allowed to, to come out . . .

In order to support the woman emotionally and socially the nurses felt they needed to treat each woman as an individual, provide a nursing presence, allow the woman to express her feelings and by listening and talking be comforting, reassuring and counseling. At interview, the nurses often stated they did not have the counseling skills nor the time, particularly in hospital, to fulfill these support needs. As one community nurse reflected:

I think they . . . [the hospital nurses] . . . are pretty rushed and that makes them feel negligent because they couldn’t do the best they could have done for the lady.

The nurse’s role in this supportive care is encapsulated in the following quote:

That day . . . [the woman] . . . had something for pain, families have come in to reassure them that they all love them and then they’re left with their thoughts. And I think having a member of staff at that stage to sit quietly with them . . . someone with them that they feel comfortable with and someone who’s not going to be rushed. It may not be the evening sister who’s giving out the sedation, but a nurse who is easy to talk with who doesn’t mind, is comfortable with silence and can just sit there for a while. While the patient, maybe, just mulls over their thoughts, who’ll confide in them and know it’s not going to go anywhere and just say talking through a few things . . . becomes more easier and is able to sleep a little bit better at that time.

DISCUSSION

The nurses in this study did see support as a major part of their role in caring for the woman with breast cancer. The main way they enacted this support was by providing information primarily on the disease process and the physical aspects of the illness. This confirms the general literature on the support needs of cancer patients in general (Derdiarian, 1987; Hack et al., 1992; Suominen, 1994) and of women with breast cancer in particular (Feather & Wainstock, 1989; Northouse, 1989). Information on the disease process including family risk, cure and prognosis, and treatment options has been highlighted as particularly valuable by women with breast cancer in studies in the UK (Luker et al., 1996) and in Canada (Bilodeau & Degner, 1996; Graydon et al., 1997). Luker et al. (1996) and Bilodeau and Degner (1996) also highlighted the importance that women place on sexuality information. However, in this present study, while the nurses see their role as supporting these concerns they did not emphasize information as an important part of the support.

The nurses in this study implied that if information on community resources is given in hospital then continuity of care would follow. This supports Suominen and Laippala’s (1993) study. As suggested by Luker et al. (1996) with shortened lengths of hospital stay this may be imposing unrealistic expectations on hospital nurses and other health professionals. It also reinforces the important place of
breast nurses in this aspect of care (Tait, 1995; White & Wilkes, 1998). The nurses at interview affirmed that hospital staff had a lack of knowledge on community resources. Hospital administrators and educators must take this in hand and provide in-service education not only for nurses, but for all health professionals.

When talking about social and emotional support the nurses gave the impression that while it was important they often did not have the time or skills to provide it. The findings point to the necessity for nurses to possess counseling skills in order to support women with breast cancer especially in regards to their altered body image and the effect breast cancer has on their social relationships. These aspects of supportive care for women with breast cancer should be essential curriculum components in preregistration nurse education and in specialist oncology nursing programs (Wilkinson, 1995).

An underlying theme that was embedded in the nurses’ responses was that supporting the woman with breast cancer is a team effort. Therefore, a shared team approach with the utilization of managed care plans by all health workers could reduce the physical and psychosocial morbidity of this disease and reduce the nurse’s sense of negligence in not supporting the women effectively.

While this paper has focused on the nurse’s perceptions of the support needs of women with breast cancer the data need to be supplemented with the women’s views. The research team is in the process of analyzing interviews undertaken with women. These interviews confirm that the nurses do not have time to provide adequate emotional and informational support and in some cases physical. The women implied that most of their support came from family and friends. The women also stated that they would like counseling from designated trained professionals.

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REFERENCES


