

# The psychosocial concerns and needs of women recently diagnosed with breast cancer: a qualitative study of patient, nurse and volunteer perspectives

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## Abstract

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**Keywords:** breast cancer, focus group, oncology, patient needs, psychosocial concerns

**Objective** To qualitatively identify the concerns and needs of Australian women recently diagnosed with breast cancer.

**Background** Breast cancer diagnosis can lead to impairment in multiple areas of psychosocial well-being, including physical, social and emotional functioning. Research has therefore begun to focus on identifying and addressing survivors' concerns and needs, with most research examining the time of treatment completion. However diagnosis and treatment are also key times of psychological need, and less is known about the psychosocial concerns and needs at these times.

**Research design** Seven focus group interviews were conducted examining three categories of participants: (i) patients diagnosed with early-stage breast cancer within the past 12 months, (ii) oncology nurses, and (iii) volunteers who work with cancer patients. Sampling was discontinued when informational redundancy was achieved.

**Setting and participants** Thirty-four participants took part in one of seven focus group meetings held in a hospital patient resource room.

**Results** A wide variety of psychosocial concerns and needs were discussed, and five specific areas of concern were identified: (i) coping with side-effects; (ii) dealing with self-concept change; (iii) stress and adjustment reactions; (iv) having to manage others' unhelpful beliefs, expectations and emotions; and (v) issues with survival and growth. There was a large degree of consistency in the concerns and needs identified by the different group categories.

**Conclusion** In general, the concerns and needs expressed were consistent with survivorship issues previously identified in the literature; however, several new insights were obtained. Clinical implications of these findings are discussed.

## Introduction

Breast cancer is the most common invasive cancer in Australian women and is the leading cause of cancer-related death.<sup>1-3</sup> By the age of 85 years, one in eight Australian women will be diagnosed with breast cancer.<sup>3</sup> However, while incidence rates have been increasing, mortality rates have been declining, with the current 5-year survival rate for breast cancer at 86.6% for Australian women.<sup>3</sup> As survival rates have improved, research has increasingly focused on facilitating psychosocial adjustment for breast cancer survivors. Survival can be defined as a process of three phases: (i) acute survival, the period of coping with diagnosis and treatment; (ii) extended survival, commencing when the patient ceases treatment; and (iii) permanent survival, occurring when the individual has lived disease-free for a sufficient period of time such that the probability of recurrence is decreased.<sup>4</sup> The present qualitative study focuses on the acute survival phase, a period acknowledged as highly stressful for women with breast cancer,<sup>5</sup> and one which can lead to short- and long-term adverse psychosocial consequences.

Following diagnosis of breast cancer, multiple areas of quality of life are impaired, including physical, social and emotional functioning.<sup>6</sup> In terms of physical health, treatment can cause fatigue, pain, nausea and vomiting, lymphoedema, menopause, sexual dysfunction, infertility and physical changes to bodily appearance and functioning.<sup>7</sup> With regard to social functioning, women may have to cope with role-transitions, changes to family functioning, and economic and vocational strain.<sup>8</sup> The development of psychological morbidity following cancer diagnosis is a source of debate in the research literature; however, the immediate emotional impact of breast cancer is more apparent. Between 23% and 56% of women experience emotional problems such as depression, anxiety, anger, confusion and helplessness,<sup>5</sup> with this distress decreasing to levels comparable with chronic disease and community populations over the course of the next 12 months for most women.<sup>6</sup> In the long term, the majority of women appear

to cope well psychologically,<sup>9</sup> with only a small percentage of women developing severe psychological distress.<sup>10</sup> However, approximately one-third of women continue to experience sub-threshold psychological problems and impairments in quality of life.<sup>11,12</sup> For example, fear of recurrence and anxiety surrounding annual check-ups may last for many years following diagnosis.<sup>7,13,14</sup>

In the context of improving the psychosocial consequences of breast cancer in the acute survival phase, research has recently begun to focus on identifying and addressing survivors' specific concerns and needs. Two recent Australian studies found that a number of concerns arose after completion of treatment regarding physical side-effects and limitations,<sup>1</sup> emotional worries regarding the future,<sup>1,14</sup> challenges to lifestyle and career,<sup>1</sup> and relationship/intimacy problems.<sup>1,14</sup> For young women, particular concerns arose regarding the implications of recurrence or mortality for their partners and children.<sup>14</sup> Research into other populations has also outlined concerns relating to family and children, physical health, body image, sexual health and possible recurrence.<sup>15-17</sup>

In terms of needs, Australian women in the extended survival period experienced three types of needs including support for: (i) psychological health, which includes informal support from family and friends, support from the treatment team, access to support groups and professional counselling;<sup>1,14,18,19</sup> (ii) practical and physical needs, such as requiring assistance with activities and travel;<sup>1</sup> and (iii) information needs, for themselves and their family.<sup>1,2,14,19</sup>

To date, Australian research into psychosocial concerns and needs has largely focused on the extended or permanent survival phases,<sup>1,19</sup> and to the authors' knowledge no study has qualitatively examined the psychosocial concerns and needs that arise in the acute survival phase. Given that the time of diagnosis and adjuvant treatment are key times for psychological intervention,<sup>20,21</sup> it is important to identify these needs as early intervention may prevent long-term psychological morbidity from occurring.<sup>22</sup> Therefore, the aim of the current study was to

gather qualitative data on the psychosocial concerns and needs of Australian women recently diagnosed with breast cancer, from the perspectives of: (a) patients themselves; (b) oncology nurses; and (c) cancer-volunteers, many of whom also had a history of breast cancer. Obtaining the perspectives of those who work closely with patients, as well as patients, can yield useful information as to the level of consistency in knowledge across group types and also whether gaps in awareness of issues exist.

## Methods and procedures

### Participants

Three different categories of participants undertook the focus groups: 'patients', women who were recently diagnosed with breast cancer; 'oncology nurses', specifically those who work with breast cancer patients; and 'volunteers', individuals who provide support services for women with breast cancer. A total of 34 participants (33 women, one male nurse) took part in one of seven focus group meetings. These included four patient groups ( $n = 19$ ), one nurse group ( $n = 6$ ), and two volunteer groups ( $n = 9$ ), seven of whom (78%) were also breast cancer survivors.

Eligibility criteria for the patient groups included a recent diagnosis (<12 months) of early-stage breast cancer (stages 0 to 2), being 18 years or older, and ability to speak fluent English. The relevant demographic and clinical characteristics of the participating patients are described in Table 1.

As regards the volunteers, it should be noted that participants fell into two categories: (i) those who had a history of breast cancer themselves ( $n = 7$ , 78%) and could provide personal as well as occupational perspectives, and (ii) those who did not have a history of breast cancer ( $n = 2$ , 22%) and thus provided occupational perspectives only. Four volunteers (44%) worked as telephone counsellors for a programme called 'Cancer Connect' that links individuals going through treatment with a survivor who had a similar cancer experience; three

**Table 1** Demographics of participants in the patient groups ( $n = 19$ )

Age (years), mean (SD)	53.50 (12.47)
Time since diagnosis [months; mean (SD)]	6.63 (2.75)
Stage, $n$ (%)	
0	1 (6)
1	9 (47)
2	9 (47)
Surgery, $n$ (%)	
Lumpectomy	4 (21)
Mastectomy	14 (74)
Bilateral mastectomy	1 (5)
Current adjuvant treatment status, $n$ (%)	
Chemotherapy	7 (37)
Radiotherapy	4 (20)
Hormonal therapy	5 (26)
Completed all treatment	3 (16)

volunteers (33%) were representatives from national breast cancer bodies; and two volunteers (29%) were representatives for their breast cancer support groups. Of the seven volunteers who had previously had breast cancer, the average time since diagnosis was 7.73 years (range = 2.25–18 years, SD = 5.75 years). One volunteer was undergoing treatment for recurrence at the time of the study.

Only occupational data were gathered for the nurse participants. Two nurses specialized in coordinating outpatient services for cancer patients, one nurse was a breast care-extended practice nurse, two nurses worked in the oncology inpatient ward, while one nurse provided chemotherapy treatment in the day unit. Therefore, every aspect related to the patient, from diagnosis through to treatment and follow-up was covered. Sampling was discontinued when informational redundancy was achieved. Focus group size varied from four to six participants, which is considered an appropriate number when the nature of the topics under discussion is sensitive.<sup>23</sup>

### Procedure

Two methods of advertising the study were utilized: (i) advertisements for the focus groups were placed around the oncology ward of a

South Australian public hospital, and (ii) the Medical Oncologist (BK) and Breast Care Nurses distributed information packs (containing an information sheet, consent form, and list of preferred days and times) to 28 consecutive patients seen in clinics who met the eligibility criteria. Only the second method proved successful as a recruitment strategy. Of those 28 eligible patients, 19 (68%) consented to participate. For the nine individuals who declined to participate, reasons stated were as follows: five patients (56%) stated that they were too busy, two patients (22%) stated that they did not feel comfortable with a group format, and two patients (22%) were experiencing side-effects from treatment that made participation difficult. Similar information packs were also distributed by the Breast Care Nurses to oncology nursing staff for the nurses' focus group. The volunteer groups were recruited with the assistance of the Cancer Council South Australia, who mailed out information packs to their registered volunteers.

Individuals who consented to participate were posted a copy of the Topic Guide to give them time to consider their answers and encourage greater depth of discussion. This guide contained eight major topic questions/domains (Table 2), which were based on the biopsychosocial model of health and the literature on post-traumatic growth.

The eight primary topic questions were supplemented with clarifying and probing questions to encourage more in-depth responses.<sup>23</sup> For volunteers and nurses, particularly for those

who had a history of breast cancer, prompts were used to keep the discussion focused on the period of diagnosis and treatment, rather than exploring issues that arise after treatment completion. All focus groups were conducted in a patient education and resource room, which was chosen to help participants feel more at ease as they were generally familiar with this environment. Hospital staff were not present during the patient groups to enable participants to talk openly.

To ensure consistency, all focus groups were moderated by a Clinical Psychology PhD candidate (LB), who received training in conducting focus groups, and a female note taker. Each focus group was audio-taped and lasted between 90 and 120 min, with the exception of the nurses group which lasted 60 min. Participants were given morning/afternoon tea, and then were seated in a circle to foster openness and facilitate discussion. All participants were encouraged to respond to all topic areas, but were informed they had the right to not respond. Each group commenced with participants briefly introducing themselves and providing some information about their cancer history (for patients), or the nature of their work (for volunteers/nurses). The provision of factual information was used to ease participants into the discussion by talking about non-threatening topics.<sup>23</sup> This study was approved by the relevant University and Hospital Research Ethics committees.

#### Data analysis

Focus groups have been widely used to examine people's experiences of disease and health services.<sup>24</sup> This methodology was chosen for the current study as it is best suited to addressing unexplored areas of enquiry,<sup>23</sup> encourages participation of people reluctant to be interviewed individually, and allows for further exploration and clarification of views that would be less accessible in a one-on-one interview.

Each focus group was discussed during a debriefing between the moderator and assistant,

**Table 2** Focus group interview domains

- 
1. Most pressing current physical need
  2. Most pressing current emotional need
  3. Most pressing current social need
  4. Useful advice for other women:
    - a. At diagnosis
    - b. Regarding staying healthy
  5. Benefits/learning opportunities of breast cancer
  6. Marking the end of treatment
  7. Special challenges of breast cancer
  8. Most confusing aspect(s) of breast cancer
-

transcribed verbatim by the assistant, checked for accuracy against the audio-tape recordings (LB), and supplemented with field notes. Two authors (LB and MO) then independently coded every transcript into categories, until all statements on a given topic were summarized (saturation point). Emergent themes were then identified, and overlapping clusters of information were combined, such that the themes were further refined. In this thematic analysis, greater emphasis was given to frequently raised themes (i.e. those repeated by more than one group), themes which raised strong feelings, or that resulted in long discussion. Agreement with regard to the final themes reported was achieved through subsequent discussion by the two authors.

The analysis aimed at identifying patient *needs* and *concerns*, from the perspectives of all three categories of participants (patients, volunteers and nurses). A particular emphasis was placed on identifying consistent areas of needs across groups, as well as gaps in awareness of patient needs between the groups. Where participants provided suggestions regarding how to meet needs or overcome concerns, these were incorporated into the relevant themes.

## Results

From the analysis, five major themes were extracted: Coping with Side-Effects, Self-Concept Change, Stress and Adjustment Reactions, Managing Others, and Survival. While some differences in observations between group categories emerged, it is important to note that there was a good deal of consensus regarding the psychosocial issues and needs.

### Theme 1. Coping with side-effects

Participants reported a range of illness and treatment-related side-effects that impaired perceived ability to cope and quality of life, including fatigue and insomnia, numbness and pain (including lymphoedema), and malnutrition. Fatigue and insomnia were mentioned frequently and with intensity across all groups

except nurses. Participants reported that the resulting state of 'exhaustion' impaired their ability to do daily activities or maintain a social life, e.g.

Everything you do is an effort. You know, if you walk up 5 stairs, you feel like you have run a marathon (Patient, aged 46).

It's one of the physical needs that I had a lot of trouble with, feeling tired. Also tiredness from radiation. Quite often I think a lot of that can be from travelling everyday (Volunteer, Support Group Leader).

Some nights I just can't sleep at all and I just put my earphones on and listen to a story or music (Patient, aged 65).

This fatigue was mentioned by participants irrespective of the treatment regime.

Numbness and pain in the arm, fingers and shoulder areas occurred for a number of women. This was widely reported across the patient and nurses group, e.g.

It's like laying on your arm and it's gone dead, and you wake up and sort of go "where is it?" (Patient, aged 51).

The postoperative pain and the arm-numbness: paresthesia in the upper arm is a big problem reported (Nurse, Breast Care Specialist).

They started off with the Tamoxifen treatments, which did nothing, then I went onto Letrisole, and that gave me fibromyalgia (Volunteer, Support Group Leader).

Lymphoedema in particular was reported by patients and volunteers to be an area of concern for two reasons: the impact on daily functioning and the lack of information given by the medical profession, e.g.

I have got some lymphoedema, and I go and have massages...but laser treatment is just wonderful! Absolutely fantastic. But nobody told me how wonderful it was. (Volunteer, Cancer Connect Program).

Interestingly, changes in appetite were extensively discussed by all patient groups, but not by the nurses or volunteers. Patients reported being malnourished due to a combination of loss of appetite, mouth ulcers, and a perceived change in taste, e.g.



I found that I needed really strong tastes, because you've got horrible taste and ... mouth ulcers (Patient, aged 45).

Other side-effects that were discussed, though not as extensively, were nausea and vomiting and menopausal symptoms. The menopausal symptoms were often described as being manageable on their own, but burdensome when combined with other side-effects.

In terms of needs arising from these side-effects, patients wanted more information about the likelihood of side-effects and how these would impact on their daily functioning. The need for practical support and advice in achieving daily physical activities such as shopping, cooking, cleaning and child care was also highlighted across all groups.

## Theme 2. Self-concept change

Women with breast cancer reported difficulties with multiple areas of self-concept, including physical, personal and social aspects. With regard to physical self-concept, body image was one of the most frequently mentioned themes by participants in all groups. Almost all patients reported that some aspect of their body image had been challenged by breast cancer, such as feeling unattractive, missing their breasts, feeling 'lopsided', and coping with weight change and hair loss, e.g.

It took me all my time, probably until after I was 40 to get used to my body and to actually like it, because I was always big ... it's like I've been ripped off, I just got used to it! I got used to accepting it, and now I have to change my thinking to accept two scars (Patient, aged 45).

They not only then feel down about ... the way they look, because not only have they possibly had a breast removed but they've lost their hair, their skin is all dry, they're getting more wrinkles and all of these other things. So they feel physically unattractive (Nurse Practitioner, Oncology).

Participants from all group types also described that breast cancer challenges women's personal self-concept such that they did not know who they were anymore, e.g.

Things are going to be different, and it is not going to be the same again. And it is just a journey into who the new person that you're going to be is... You are a different person (Patient, aged 37).

It makes the hair fall out, and they feel like they've lost part of their womanhood (Nurse, Breast Care Specialist).

Personal role-change at home was another area reported by all participants as being impacted following diagnosis, with women saying that their normal 'duties', such as picking children up from school, cleaning the house, or cooking, had to be delegated to others at times, e.g.

My husband really, really does try. He really tries. He's trying – we'll just leave it there! But it is never right and I find it difficult to just sit there and just let it go (Patient, aged 37).

Participants also reported changes in social roles, saying women were not able to continue their level of involvement in certain activities, such as work, volunteering or sport, e.g.

It's hard when you are going through something and there are multiple things happening. I just withdrew from all church work. I just couldn't do it just for a little while (Patient, aged 51).

I've never had so much time by myself, because I didn't work because of the area I worked in (Volunteer, Cancer Connect Program).

Participants from all groups then discussed resulting needs. In terms of physical self-concept, these needs largely related to: (i) finding ways of increasing bodily self-esteem and femininity, including finding attractive lingerie, using a wig if hair loss occurred, and making use of programmes that teach make-up strategies to disguise the side-effects of treatment; and (ii) accessing emotional support for change in bodily appearance. In terms of personal and social self-concept, the need most frequently and intensely mentioned across all groups was maintaining a sense of identity separate from being a 'breast cancer survivor'. This included trying to maintain a normal lifestyle where possible, and refusing to be labelled as a 'survivor' or a 'patient' by their social circle. One final need that was raised by patients and nurses

included learning how to accept help and short-term role change.

### Theme 3. Stress and adjustment reactions

A number of stress and adjustment difficulties to diagnosis, treatment, and treatment-completion were reported by participants across all groups. At diagnosis, participants from all groups reported feeling fear, shock and/or anguish/distress, e.g.

You don't realise it, you are in shock when you are first told it... You just want to close off to it too (Patient, aged 63).

Another common reaction was anger, with patients stating that they had done all the right things and still got cancer. This thought pattern and resultant anger made adjusting to their diagnoses more difficult, e.g.

Particularly the patients who are vegetarian, don't drink, don't smoke, go to the gym five times a week...they have more difficulty coming to terms with it (Nurse, Cancer Care Coordinator).

Another reaction participants raised with strong feelings was self-blame for their diagnoses, e.g.

If only I had done this, if only I hadn't done that, then I wouldn't have got [breast cancer] (Patient, aged 62).

During treatment, participants from all groups noted that isolation, depression, helplessness and loss of control were commonly experienced, e.g.

I just felt really uncontrollable, thinking that I should know what to do and I don't. That was a horrible feeling. Not being in control, not knowing what to do, having so many options (Patient, aged 44).

If you don't have the responsibility of work and family and all of that, you can tend to become a bit insular and dwell on things (Volunteer, Support Group Leader).

Women also reported having 'delayed distress' where they believed they had been coping really well earlier, but were now 'falling apart', e.g.

I can't understand it because I was so tough. Didn't shed a tear... but now I'm hopeless! (Patient, aged 65).

For some individuals receiving treatment, this was also the time when anticipatory nausea or other anxiety responses occurred.

Feelings of isolation appeared to intensify after treatment completion, with many women feeling like they have been abandoned by their medical team, and also reporting that friends started to withdraw social support at this time, e.g.

You feel very alone at times (Patient, aged 51).

They finish chemo and then what is next? They feel really left high and dry, a lot of women. Like they have come to the hospital every, you know, couple of weeks. They have seen all these health professionals that have been involved and then it's like you are out there (Nurse, Oncology Ward).

Another major emotional issue at treatment completion was anniversary-related anxiety and depression, e.g.

I still have black days, and the anniversaries, you know, some shroud comes over me (Volunteer, Cancer Connect Program).

When I see my surgeon every year now I come out and I go 'yes! Yes!' You know I feel for just 5 minutes I'm free. You know just that little surge. [But going in,] I'm a cot case! (Volunteer, Cancer Connect Program)

They'll have anniversary symptoms syndrome... Some of them are almost physically sick with fear (Nurse, Breast Care Specialist).

Participants from all groups also expressed a number of emotional adjustment needs related to increasing a patient's sense of control. These included exercising personal choice, filtering incoming information to minimize the likelihood of being overwhelmed, finding opportunities for emotional expression, needing to maintain normality wherever possible, and the need to look for the positives.

### Theme 4. Managing others

This theme covers the issues women with breast cancer experienced in dealing with members of

their social network, including managing the unhelpful expectations, beliefs and emotions of family and friends. Patients sensed that some individuals could not handle their diagnosis:

A woman I was very close friends with, she would just tear herself into pieces (Patient, aged 46).

The issue most strongly emphasized was having to maintain a front or 'game face' with friends, which resulted in a sense of decreased support:

You have to keep up this bloody 'front' in front of everybody, and everybody expects it. And if you let it down they say "oh you mustn't be negative!" (Patient, aged 62).

Even now people look at me and they say 'oh, how are you'? And you know, I sit there going 'I'm fine!' (Volunteer, Cancer Connect Program).

This concept was mentioned by all patient groups and one volunteer group, but was not mentioned by the nurses.

Another issue related to managing others was the impact on patient's partners and children. The patient groups widely reported experiencing concern for their partners who experience their own stress and adjustment difficulties without the same access to social support, e.g.

The partners cop it, yeah they do. They are amazing in that they keep going and do everything and yet you know they are dealing with a hell of a lot in their head and they are just not showing it to us (Patient, aged 33).

Related to this, relationship issues were raised by all groups. Break-ups were mentioned by the volunteers and nurses groups, while intimacy difficulties were reported by two patient groups:

We've had two in just a small group who've lost their husbands because of their breast cancer. Very tough (Volunteer, Support Group Leader).

Sometimes it can actually bring all those relationship issues to the fore. A diagnosis makes them question what's important or where their relationships are at (Nurse, Oncology Ward).

It kills your sex life! (Patient, aged 62).

[Sex] is just the last thing in the world you want to do (Patient, aged 56).

In response to these social issues, ways of increasing social support were identified. These included: (i) talking to someone who has been through the journey before; (ii) identifying 'cold weather' people who will be there through thick and thin; (iii) increasing communication with the medical profession as a source of support; and (iv) identifying sources of instrumental support, who can assist with travel, attend appointments with you, and provide help with domestic chores.

### Theme 5. Survival and growth

This theme covers the uncertainties that women with breast cancer experience regarding their ongoing prognosis and possible mortality. Patients and volunteers indicated that the lack of closure at treatment completion was a difficult concept to deal with, particularly the fact that there is no final test to confirm that the cancer is gone, e.g.

Everybody asks me "Is everything clear?" But how do you know? There is no such test (Patient, aged 50).

My oldest daughter says "is all the cancer gone from your body?", and I said "probably not, but we don't know...I'm hoping it is, but you don't know if there is any more there" (Volunteer, Cancer Council).

To overcome this need, all groups listed other ways of seeking closure, including having celebratory dinners with family and friends, morning teas with the medical team, and ceremonies to destroy or donate wigs and scarves.

Participants from all groups widely mentioned the issue of coming to terms with the possibility of dying, and indeed some women reported feeling as though they were on death row, e.g.

I just realised very much about myself that I am not coping at all with my own mortality (Patient, aged 62).

The mortality part was a challenge. Right in the beginning, because I think a lot of [women] think they are going to die (Volunteer, Support Group Leader).



Several participants reported not having the opportunity to express this awareness to a support person. Participants from all groups state that some women make a conscious decision to focus on living and having quality of life, rather than ruminating on the possibility of dying, e.g.

My whole death thing has changed, I'm just not worried about it... I think I'm right in the living for today thing, and I don't actually care. On my gravestone I want it to read that they can't remember how I died but they remember how I lived (Patient, aged 44).

One related area of uncertainty regarding survival is coping with the ongoing fear of recurrence. Participants from all groups described this as playing a 'waiting game', e.g.

There is always the chance of this coming back somewhere along the track. And you know, every little ache and pain that you get, is this it back again? (Volunteer, National Representative).

In response to these survival issues, patients expressed a need to focus on their consequent growth, e.g.

Even this cloud can have a silver lining... I'm going to get emotional now, I do think that a lot of positives have come out for me (Patient, aged 30).

Specific benefits included having a new perspective on and appreciation for life, having a sense of inner strength and ability to cope, learning to prioritize themselves more and taking time out, and improving some relationships.

## Discussion

In this study, women recently diagnosed with breast cancer, oncology nurses and breast-cancer volunteers were consulted, with the aim of determining concerns and needs that would be beneficial to address. In general, the concerns and needs expressed were consistent with survivorship issues identified in the literature,<sup>6-8,14,18</sup> however, several new insights were obtained.

Participants from all group categories identified five broad areas of concern, including coping with side-effects, adjusting to changes in self-concept, dealing with stress and adjustment difficulties, managing others' expectations and

emotions, and survival issues and growth. In response to these concerns, a range of specific personal and social support needs were also identified. Patients want to increase bodily self-esteem, foster and maintain a non-breast cancer identity, focus on personal control, and explore the benefits of diagnosis. Consistent with Bloom's theory of psychosocial support,<sup>25</sup> informational, instrumental and emotional social support needs were identified by all participants. More specifically, rather than wanting an intervention to *reduce* side-effects, patients described needing information to *normalize* side-effects and how these would impact on daily functioning. This is also consistent with the needs of longer-term survivors,<sup>1,2</sup> suggesting that the need for normalization commences early and is ongoing. In keeping with previous Australian findings,<sup>1,14,18</sup> patients also emphasized the need to have core support people, and to speak to someone who has been through the journey before.

These findings have clinical implications for informing service providers. While many patient education guides address physical and medical concerns,<sup>26-28</sup> fewer present detailed information relating to psychological concerns. Research into health prevention indicates that provision of information is not enough to effect change,<sup>29,30</sup> therefore such resources or interventions should encourage patients to actively process their concerns. These resources are currently scarce or inadequately promoted. For example, although there are 'Cancer Connect' telephone programmes run by cancer councils in Australia designed to meet the emotional need of linking recently diagnosed women with longer-term survivors, very few patients in the present study mentioned accessing this programme. This is consistent with a previous study that found that only 4% of participants used cancer telephone services.<sup>19</sup> Indeed, when this programme was mentioned in the present study, most participants in the patient groups stated that they were unaware of its existence. Thus greater promotion of this and similar programmes by the medical team may be warranted. Other needs, such as

how to foster a sense of identity that does not involve breast cancer, may require innovative interventions or access to professional counselors. Extrapolating from the present findings, a self-help workbook may be an effective method of addressing these needs, and preliminary research evidence supports this.<sup>31</sup> Medical practitioners should routinely check for the presence of these concerns and needs, and establish referral pathways to relevant specialists or to available programmes.

While many of the concerns and needs identified in the present study were consistently reported across the different categories of groups, there were three major specific concerns raised by patients and volunteers that were omitted by nurses: (i) coping with fatigue; (ii) maintaining a 'game face' (professional front); and (iii) coping with the uncertainty of treatment success. Given that fatigue is considered the most prevalent and debilitating symptom experienced by patients,<sup>32</sup> and impairs quality of life,<sup>33</sup> it was surprising that nurses did not discuss this issue in the present study. However, there are two possible reasons for this omission that have been described in the research literature;<sup>7,34</sup> first, that patients are often reluctant to report fatigue to their treating professionals who therefore may be unaware of the extent of the problem, and second, that healthcare providers frequently do not screen for fatigue because they are uncertain how to manage it. It may be useful to hold educational seminars for health professionals on how to manage fatigue, including ideas used with chronic fatigue patients such as pacing activities and setting realistic goals.<sup>35</sup>

It is less surprising that nurses did not discuss having to maintain a 'game face' around family and friends, as this particular concern may not be routinely mentioned to health professionals. Patients possibly choose not to disclose this concern because they believe that the issue is not medically related; however, as loss of social support has a significant impact on psychosocial and physical functioning,<sup>36,37</sup> it is important for health professionals to be aware of and check for the presence of such concerns. Finally, although nurses in the present study were aware

of several survival concerns that arise *after* treatment completion, they did not discuss the lack of closure and the uncertainty of treatment success that occurs *before* the end of treatment. This is in line with the lack of empirical research, as only one qualitative study has previously examined transitional needs and concerns.<sup>38</sup> Although health professionals cannot provide patients with a final clearance test to provide that sense of certainty, there are other ways of promoting closure for patients, such as celebratory dinners and wig-burning ceremonies, which should be discussed.

The present study provides several unique contributions to the research literature. Although communication difficulties have previously been mentioned in the research literature, this was the first time the 'game face' concept and its impact on social functioning have been mentioned. This contrasts with previous research that stated that social functioning is least affected.<sup>6</sup> While several studies have highlighted the need for social support,<sup>1,14,18,19</sup> to the authors' knowledge no study to date has described this particular form of loss of social support. Similarly, although previous research has identified self-concept change and body image as major issues for women,<sup>39-42</sup> the present study is the first to identify the specific associated need of increasing bodily esteem, maintaining identity separate from breast cancer, and providing suggestions for doing this. Another unique aspect of the present study was comparing the perspectives of patients and support providers with those of nurses to identify gaps in knowledge and awareness.

The main limitation of this study relates to the self-selection of the sample, which means that the views may not be representative of these various groups as a whole. However, there was a high level of consistency in the issues reported across the different group categories and saturation of themes was reached. Because of the qualitative nature of this study, further quantitative research is warranted to determine the prevalence of the needs identified in the present study and to test the validity of these findings in a larger sample. A second minor limitation was

that only occupational data were collected for nurses, thus whether their diverse ages and years of experience may have had an impact on the results is unknown. It should also be noted that the volunteer participants who had a history of breast cancer made a mixture of self-referential as well as occupational observations. Thus there may have been a recall bias during discussions, such as commenting on longer-term experiences. However, measures were taken to minimize this bias, such as the use of prompts to focus on the period of diagnosis and treatment. Given the level of consistency in themes reported across all group types, this limitation is likely to be minor. Within the context of these limitations, this study presents emerging themes and useful preliminary information about women's self-identified current concerns and needs at diagnosis and during treatment, rather than relying on retrospective recall of information.

In summary, the findings of the current study demonstrate that the acute survival period of breast cancer is clearly a time when women report a number of concerns and needs. Despite the best efforts of the medical treatment team to provide information and support throughout formal treatment, some of these needs appear to go unmet. These highlighted areas of need require suitably matched interventions that can be offered during the acute treatment phase so that women feel their needs and issues are understood and shared.

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