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## Assessing the Support Needs of Women With Early Breast Cancer in Australia

### KEY WORDS

Australia  
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Family  
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Support

The purpose of the current study was to assess the degree to which the support needs of women with a newly diagnosed, early invasive, primary breast cancer and their families are being met. A random sample of 544 women diagnosed with early breast cancer was recruited to participate in a telephone survey via state and territory cancer registries. Sixteen percent of women reported not receiving enough support during their diagnosis and treatment, and only 65% of these women reported that their families received enough support. The primary sources of support for women and their families were medical practitioners (eg, surgeons, oncologists, and general practitioner) with very few women or family members utilizing mental health professionals. Given the importance of adequate support when being diagnosed and treated for breast cancer, urgent attention needs to be paid to training medical professionals in providing appropriate support and referrals for their patients.

As in other Western countries, breast cancer remains the most common cause of cancer deaths among women in Australia.<sup>1</sup> In addition to the physical suffering experienced by women diagnosed with breast cancer, there is considerable emotional suffering for these women and their families. A woman with breast cancer is likely to be faced with multiple concerns during her diagnosis and treatment of breast cancer, such as coping with treatments, financial strain, child-care issues, employment concerns, and future health concerns. Researchers have proposed 2 theories, the “buffering” and the

“direct effects” hypotheses, to explain how support influences health and well-being.<sup>2,3</sup> According to the *buffering hypothesis*, support affects health and well-being by protecting the person against the negative effects of high stress, whereas the *direct effects hypothesis* maintains that support is beneficial to health and well-being regardless of the amount of stress people are experiencing.<sup>2,3</sup> Regardless of the theory, both agree that support is beneficial to health and well-being.

The extent to which a woman has support and feels supported, has been identified as an important factor in women’s

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adjustment to breast cancer.<sup>4-10</sup> Women with poor support are more likely to experience the additional burden of psychological difficulties.<sup>6,8-10</sup> Although breast cancer can be stressful for all women, younger women are likely to face unique concerns and may be in particularly need for additional support.<sup>11</sup> Randomized controlled trials have shown that women with breast cancer who were provided with an opportunity to explore feelings with a member of the treatment team or a counselor had less psychosocial distress than women not provided with this opportunity.<sup>12-14</sup> Randomized controlled trials also demonstrated that women who received supportive care from a specialist breast nurse had lower rates of psychological distress, such as depression and anxiety, and increased levels of knowledge about treatment compared to those who did not receive such care.<sup>13,15</sup> Recently endorsed psychosocial clinical practice guidelines have recommended that members of the treatment team take an active role in offering emotional support to women at each contact.<sup>16</sup>

Good support from family and friends is a protective factor, and lack of support may be associated with a poorer emotional adjustment.<sup>4,5,8,9</sup> While social support can be provided by family and friends,<sup>4-10</sup> in at least some cases, women may be reluctant to disclose fears or be wary of distressing and overburdening their partners and others in their immediate support network.<sup>17</sup> Additionally, family members themselves may have high rates of psychological morbidity,<sup>17,18</sup> and need external support themselves.<sup>19</sup>

The importance of support for women with breast cancer is clearly documented in the literature; however, the extent to which women's and their families' supportive needs are being met in routine care following a diagnosis of early breast cancer remains unclear. Thus, the purpose of the current study is to assess the degree to which the support needs of women diagnosed with early breast cancer and their families are being met in Australia. There are special challenges in assessing supportive care in Australia; there is a mixed health system with approximately 50% of women with breast cancer being treated in the private sector and the remainder in the public sector.<sup>20</sup> Private sector care is often provided in the individual rooms of clinicians rather than in a clinic. Thirty percent of Australian women with breast cancer live in rural or remote parts of Australia, which are sparsely populated and where some healthcare services, including supportive care services, are often unavailable.<sup>20</sup> There is a division of responsibility for health between states and the federal government.

Specifically, the present article aimed to determine answers to 4 research questions:

- Who did women turn to for support after their diagnosis of breast cancer?
- Did women find the support they received after a diagnosis of breast cancer to be adequate for their needs?
- Did women with breast cancer receive adequate information about additional available sources of support?
- What support was available for members of a woman's family following a breast cancer diagnosis and treatment?

## ■ Methods

### Participants and Procedures

A random, population-based sample of 544 women diagnosed with early breast cancer between March 1, 1997, and August 31, 1997, were recruited for the study via the state and territory cancer registries (except Tasmania) within the first 6 to 12 months following their diagnosis. The number of women selected from each state and territory was proportional to the number of women diagnosed with breast cancer in each state and territory according to 1994 statistics (the most recent published statistics at the time of data collection).<sup>21</sup> A population-based sample was used in order to capture the state of care provided across the diverse healthcare systems (eg, private/public, rural/urban) currently operating in Australia. The period of 6 to 12 months following diagnosis was selected on the basis that the experiences of diagnosis and treatment would be relatively recent and hence, likely to be better recalled by women. Furthermore, by 6 months the majority of women would have completed their active treatment phase (ie, surgery, radiotherapy, and adjuvant therapy). Women were considered eligible to participate in the study if they met the following:

- had newly diagnosed, early invasive, primary breast cancer confirmed histopathologically. (That is, a tumor of less than 5-cm diameter, with either impalpable or palpable but not fixed lymph nodes and with no evidence of distant metastases. This corresponds to tumors that are T1-2, N0-1, M0 as currently defined by the UICC.);
- received their diagnosis within the preceding 6 to 12 months;
- were aged over 18 years;
- were not considered by their surgeon or GP to be too ill to participate;
- spoke and understood English sufficiently well to complete the survey; and
- were not considered by their primary clinician to be too psychologically or emotionally disturbed to complete the survey (eg, suffering major depression or psychotic).

Prior to contacting women to participate in the study, the primary clinician (usually the surgeon) was sent a letter asking them to indicate if their patient(s) were eligible to participate in study (eg, not too ill or psychologically/emotionally disturbed to participate, correct diagnosis, and English speaking). If deemed eligible by their clinician, women were informed about the study by letter from the registry. The letter explained to each woman how her name was identified, provided her information and a telephone number about the survey, and a consent form and reply paid envelope for her to indicate whether or not she would be willing to be contacted about the survey. Eighteen percent (18%) of women were excluded by clinicians who refused to participate in the study and 9% were excluded by participating clinician based on the eligibility criteria. The overall response rate for women was 65%.

The survey instrument was developed by a multidisciplinary team, including consumer representatives, and showed

**Table 1 • Demographic Data of Women With Early Breast Cancer (N = 544)**

	N (%)
Marital status	
Never married	26 (5)
Married/defacto	389 (72)
Separated/divorced/widowed	129 (24)
Children	
None	72 (13)
≤18 y	100 (18)
>18 y	394 (83)
Education level	
Secondary or below	150 (27)
School/higher school certificate	224 (42)
Tertiary	168 (31)
Residence	
Rural	37 (29)
Urban	63 (71)
Patient status	
Public	234 (43)
Private	308 (57)

Note: Percentages may not add up to 100% due to missing data.

satisfactory psychometric properties.<sup>22</sup> Prior to the commencement of the study, the survey instrument was pilot tested on a convenience sample of 50 women diagnosed with early breast cancer. The survey exhibited good face validity and validity was further confirmed by validating 2 items in the pilot study against medical records. The survey also had good item reliability, with the majority of core items scoring above 0.6 in Kappa analysis. After revision of some questions, test-retest reliability was again calculated with 45 randomly selected women indicating good item reliability among core items (Kappa value > 0.6). Examples of items on the questionnaire were “Did you feel like you received enough support during your diagnosis

and treatment of breast cancer?” and “Did you receive enough information about different aspects of treatment and support” with responses of “I received enough support (*or information*),” “I would have liked more support (*or information*),” “I would have like less support (*or information*),” or “can’t remember.” An independent survey-research company was contracted to conduct the survey using a computer-assisted telephone interview (CATI) system. All interviewers were women and participated in a half day training program provided by the research team designed to inform them about breast cancer in general and issues associated with women who have had a diagnosis of breast cancer.

## ■ Results

### Demographic Data

Participants ranged in age from 26 to 94 with an average age of 58.5 years (SD = 12.2). As shown in Table 1, the majority of women were married or living with a partner, had a high school education, had children over 18 years of age, lived in an urban area, and were treated as a public patient.

### ■ Who Did Women Turn to for Support After Their Diagnosis of Breast Cancer?

Participants were asked to indicate from whom they received support during their diagnosis and treatment of breast cancer. The data reported in Table 2 provide an indication of the different individuals and groups women received support from in response to their breast cancer diagnosis and treatment. The most frequently reported sources of support were medical

**Table 2 • Sources of Professional and Volunteer Support for Women With Breast Cancer and Their Families**

Support	Women’s Rank	% Women	Family Rank	% Families
Surgeon	1	58	1	37
Family doctor	2	53	2	20
Oncologist	3	37	3	17
Breast cancer survivor (volunteer)	4	36	6	5
Breast nurse	5	28	4	7
Nursing staff	6	22	5	6
Community-based support group	7	13	7	3
Telephone help-line	8	12	7	3
Counselor, psychologist or psychiatrist	9	11	9	2
Naturopath or natural therapist	10	8	11	1
Social worker	11	7	9	2
Others		53		34

practitioners, including surgeons, the family doctor, and oncologists. Mental health professionals were ranked only just ahead of naturopaths and natural therapists as sources of support while a third received support from volunteer breast cancer survivors.

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## ■ Did Women Find the Support They Received After a Diagnosis of Breast Cancer to Be Adequate for Their Needs?

Sixteen percent (16%) of women surveyed reported not receiving enough support during their diagnosis and treatment, and 11% reported needing more support from members of their treatment team. The data were examined to determine how women from different demographic clusters rated the support they received. There was no significant difference in ratings of support during their diagnosis and treatment based on age (<50 vs >50), residence (urban vs rural), patient status (public vs private), or family burden (having young children ≤18 vs >19 or no children). Women with a tertiary education, however, were less likely to rate the level of support they received as adequate compared to women without a tertiary education (75% vs 85%;  $\chi^2 = 6.36, P > .05$ ).

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## ■ Did Women With Breast Cancer Receive Adequate Information About Additional Available Sources of Support?

During their diagnosis and treatment, 69% of women reported that they were provided with adequate information on where to obtain additional support or counseling for themselves or their families. Demographic variables, including the woman's age, residence, patient status, or family burden (having young children) did not account for variance in ratings. Women who were tertiary educated were, however, significantly less likely than less educated women to rate the information they received about additional sources of support as adequate (62% vs 71%, respectively;  $\chi^2 = 4.0, P > .05$ ).

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## ■ What Support Was Available for Members of a Woman's Family Following a Breast Cancer Diagnosis?

According to the women surveyed, the sources of support their family members received when they were diagnosed and treated for breast cancer are shown in Table 2. Once again the main sources of professional support was from medical practitioners, especially the surgeon treating the woman. According

to the women surveyed, few family members received support from a mental health professional or accessed community support groups.

Only 65% of women felt that their families receiving enough support during their diagnosis and treatment, and 14% reported needing more family support from members of their treatment team. When the data were examined in relation to demographic variables, there was no significant difference related to place of residence, private or public healthcare, woman's education, family responsibility (caring for young children). Significantly more younger women reported that their families did not receive enough support compared to older women (29% vs 20%, respectively;  $\chi^2 = 9.75, P > .05$ ).

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## ■ Discussion

The study explored the views of women about the support they received and their families received following a diagnosis of early breast cancer. A broad and representative sample of Australian women participated in the telephone interviews and responded to questions about the professionals or volunteers they turned to for support, how adequate the support they received was, and how well their family members fared as well. The study used a population-based sample to capture the state of psychosocial care provided across the diverse healthcare systems (eg, private/public, rural/urban) currently operating in Australia.

The first question addressed in this article asked women who they turned to for support. The study found that more than half of the women relied upon their surgeon for support and the top 3 ranked sources were medical practitioners. The findings were reminiscent of those by Meredith et al<sup>23</sup> who reported that medical practitioners were the preferred sources of information about cancer. The fact that the majority of women turn to their surgeon for support underscores again the importance of adequate training for surgeons and oncologists in communication skills, especially in responding to strong emotions.<sup>24,25</sup>

Only a quarter of women turned to a breast nurse for support. Much of this may have been because of the lack of available specialist breast nurses in Australia, but we do know that when they are available, women strongly endorse the quality of care and support they received.<sup>26</sup> As few as 1 woman in 10 accessed professional psychological support from a counselor, psychologist, or psychiatrist, despite previous studies estimate that at least double and possibly 4 times that figure have clinically significant anxiety and depression.<sup>12,27,28</sup> Thus, many women may be missing out on potentially helpful sources or support by not seeking out services from a counselor, psychologist, or psychiatrist. We know from national prevalence studies that 70% of Australian women with comorbid physical and psychological conditions do access professional help for their psychological difficulties, and this includes 60% from the family doctor, 16% from a psychiatrist, and 13% from a psychologist.<sup>29</sup> The current data compare poorly with this figure and warrant more research to determine why more women are not

receiving specialist psychological care, if they do indeed need such services.

Support for families raised similar concerns. Again, given the prevalence studies already conducted,<sup>30</sup> as many as 43% of partners of women with breast cancer will have a psychological disorder, but in the present research only 2% of women reported that their family members were receiving support from a mental health professional.

The study found that lay organizations played a role in support for women and their families. About a third of women received support from a breast cancer survivor, and about 1 in 10 women attended a community-based support group. More needs to be done to determine the role that volunteers can play and how women benefit from these sources of support.

Overall and despite the objective low uptake of an available professional support, only 16% of women reported wanting more support. Importantly, more educated women were dissatisfied with information about support services, although we do not know enough about why they want more information on support or their reasons for dissatisfaction. Finally, there was no difference reported in the support provided to women or their families from the public and private healthcare systems or rural and urban setting (despite great geographical distances and lack of available supportive services in rural areas). In the Australian healthcare system access to support remains equitable, according to this survey.

It is important to consider several limitations of the study. Although the study included a random sample of women with early breast cancer, there is a possibility that those women who chose not to participate or were excluded from the study differed from participating women, and the results cannot be generalized to non-English speaking women. Because of the nature of self-report and time delay of 6 to 12 months, a potential recall bias may also exist. Finally, the women themselves can only provide their judgment of what adequate care is, and their views about their family's supportive care may not be accurate. Given the gaps between community availability of mental health services, and those that they could access for themselves or their families, their knowledge of adequate and community standards may have changed their responses.

In summary the present study has found that the majority of women with breast cancer turn to medical practitioners, especially their surgeons, for support, yet only a small minority access trained mental health professionals. Similarly their families rely upon the breast surgeon or family doctor. Given the high level of psychological morbidity that has been reported, and comparative access to mental health professionals in the general community, urgent attention needs to be paid to improve this access and to train medical practitioners to provide appropriate support and referrals for their patients.

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