

EVALUATION OF A SUPPORT WORKSHOP FOR PARTNERS OF BREAST CANCER PATIENTS: A PILOT STUDY

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Abstract

In a pilot study, we undertook to assess the efficacy of a support workshop for partners of women with early stage breast cancer. Thirteen male participants attended a two hour discussion group facilitated by a male facilitator. Open-ended and close-ended items specifically designed for this study were utilised to investigate the effects of attending the support workshop. The mean satisfaction scores indicate that partners found attending the workshop very useful. It was found to reduce their sense of isolation and improved perceived support, future outlook, ability to support their partners and families and their understanding of the emotional impact of breast cancer on partners. While a relatively large number of partners indicated a preference for an on-going group, fewer men indicated planning to keep in contact with others in the group. Despite having several limitations including small sample size, lack of a control group and pre-workshop assessment, the results indicate that partners believe it is important to have support groups available for them. This pilot trial has provided preliminary evidence that support groups for partners of women with early stage breast cancer are feasible and effective in meeting partners' self-reported support needs in the Australian setting.

Each year, approximately 11,500 women are diagnosed with breast cancer in Australia.¹ As well as experiencing feelings of fear, distress and grief subsequent to diagnosis, approximately half of these women suffer from anxiety and depressive disorders.² While cancer significantly impacts on the functioning of these women, it also affects every member of their families and hence cancer is often recognised to be a family disease.^{3,4} Social support and in particular, support of family members, can be of crucial importance to cancer patients' adjustment, well-being and even their survival.^{5,6} In this context, partners are widely recognised as playing a special role for these patients.^{6,9} Partners are regarded by patients as the most valuable source of emotional support⁶ and are involved in meeting many of the patients' social and emotional needs.⁵

Emotional and instrumental support from partners at pre-surgery has been shown to decrease distress at post-surgery for breast cancer patients,¹⁰ while emotional adjustment in women with breast cancer can be predicted by marital support.¹¹ It has been found that a strong relationship with an adult partner decreased the effects of depressed mood for patients,^{10,12} as well as easing the consequences of maternal depression for the children in the family.¹² Emotional support from partners has also been identified as being related to decreased physical problems over time for patients with a recurrence of breast cancer.¹³ It has been suggested that the partner's availability provides comfort and reassurance for these women, enabling them to find some positive meaning in their experience and so facilitate their adjustment.¹³

While support by partners and families plays a crucial role in the adjustment of breast cancer patients, these men* and their families experience considerable stress themselves.¹⁴ Baider points out that it cannot be assumed that the family, and in particular the partner, can be natural supporters of the breast cancer patients, but that they may themselves also require help and support.³ The partner of a breast cancer patient may become increasingly more vulnerable as he faces two challenges: being the primary supporter, he is required to assume new roles in the home and provide instrumental as well as emotional support; while at the same time he must cope with the distress of his wife's diagnosis, her suffering and threat to her life.¹⁵ There are enormous demands on the partner as the primary caregiver for both the patient and the family.¹⁴ When a partner's distress level is high and he uses ineffective strategies, he is less likely to be capable of providing support.¹⁵

While partners often seem to worry more than the patients themselves, they frequently report receiving less emotional support than the patients.¹⁶ While the crisis of cancer draws attention to the needs of the patient, partners may be left to cope with little or no support.¹¹ It has been suggested that group support for the partners of women with breast cancer may be a potentially effective treatment intervention as it may reduce isolation, allow partners to share feelings and claim some much-needed time for themselves.¹⁷ In taking care of their own needs, this may facilitate a greater sense of empathy for the women.¹⁷

* Previous research has investigated only male partners of female breast cancer patients. The current study is also an investigation of male partners, and the term 'wife' is used to refer to the breast cancer patient.

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Few resources currently exist to provide support to partners of breast cancer patients and there is little literature available on the efficacy of support services for these men. A systematic literature search revealed only two previous intervention studies specifically focused on support groups for partners of breast cancer patients.^{18,19} Sabo, Brown and Smith compared partners of mastectomy patients that attended 10-weekly two-hour discussion sessions using two facilitators, with partners that did not attend such a group.¹⁹ Results showed that support group members became significantly more communicative with their partners about cancer-related issues and it was concluded that support group experience facilitates adjustment of partners of women who have undergone mastectomy.¹⁹ This intervention included six partners in the group and the outcome was measured using self-reported responses to a study-specific questionnaire.

In a pilot study, Bultz, Specia, Brasher, Geggie and Page conducted a randomised controlled trial of a brief psycho-educational support group consisting of six weekly 1.5–2 hour sessions for 15 partners of early-stage breast cancer patients.¹⁸ Three months post intervention, partners had less mood disturbance compared to controls.¹⁸ The men in this study emphasised the experience of feeling normalised through being able to compare their experiences with those of the other partners.¹⁸ Also, patients whose partners attended the support group reported less mood disturbance, greater functional support and greater marital satisfaction.¹⁸ Patients reported that receiving the intervention helped their partners to be better caregivers (86%), and contributed to both an increase in communication (57%) and improvements in their relationship (43%).¹⁸ Patients also indicated that the group sessions provided a stimulus to subsequent intimate conversations with their partners and that their partners were more able to listen, comfort and support them as a result of their participation.¹⁸

Due to the limited preliminary results of previous research on support groups for partners and the lack of such precedence in the Australian setting, a trial of a group intervention for partners of early-stage breast cancer patients was carried out. As previous studies in this area have been conducted in the US and Canada and notions of masculinity are at least in part culturally determined, it is important to assess the efficacy of support groups for partners in different cultural contexts. This pilot study aimed to examine the feasibility of a group intervention for partners, to explore the needs of partners in relation to such a group and the appropriateness of the structure of this intervention in meeting those needs. In particular, this study aimed to investigate the effects of attending a support group on partners' sense of isolation, perceived support, future outlook, ability to support their partners affected by cancer and their families, and their understanding of the emotional impact of breast cancer on partners. It also aimed to explore whether participants intended to form support networks with other participants and if they preferred an ongoing group or a one-off meeting.

Table 1
Summary characteristics of participants (N=11)

VARIABLE	%
<i>Age (mean 56.3 years, range 36-77)</i>	
30-39	22
40-49	22
50-59	11
60-69	11
70-79	33
<i>Level of education</i>	
Trade/apprenticeship	33
Certificate from college/ TAFE	33
Bachelors degree	22
Postgraduate diploma/degree	11
<i>Language spoken at home</i>	
English	89
Other	11
<i>Marital status</i>	
Married	89
Not married, living together	11
<i>Length of relationship (mean 28.9 years, range 10-51)</i>	
10-19	44
20-29	0
30-39	33
40-49	11
50-59	11
<i>Children</i>	
No	22
Yes, from previous relationship	11
Yes, from current relationship	56
Yes, from both current and previous relationships	11

Partners' views on the importance of the availability of such support groups, how such a service could be improved and what other services would further assist these men in dealing with their partners' breast cancer were also explored. This pilot study intended to provide recommendations for developing an appropriate support group intervention for partners. For this purpose, it was designed as a process evaluation to elucidate support provision processes by investigating the content and the quality of the group, rather than an outcome evaluation focused on quantified degrees of participant outcomes.

Methods

Participants and recruitment

The participants of this study were partners of women with early stage breast cancer, selected in line with the study by Bultz et al¹⁸ due to the relative homogeneity within this stage of the disease, ensuring similarities of issues and challenges faced by patients and partners. A letter of invitation was mailed to 148 women who had attended the Randwick Campus of Prince of Wales

Hospital between September 2000 and March 2002, inviting their partners to attend a two-hour workshop. A flyer included with this invitation letter explained that an information and discussion evening would be hosted for partners of women with a diagnosis of early breast cancer to facilitate meeting other partners, and hearing about the resources and strategies which helped them and their families. Only women who were known to have partners were contacted. Thirteen partners (9%) accepted the invitation and attended the workshop.

Procedures

This group aimed to provide support through facilitating an open discussion of issues faced by partners, allowing partners to hear others' struggles and their ways of coping with similar challenges. For this purpose, and based on the researchers' extensive counselling experience and their clinical observations, an unstructured discussion group design was selected. Due to the pilot nature of this study and time limitations for the duration of this trial group, similar to the study by Sabo, Brown and Smith¹⁹ our strategy focused on primarily providing support. However, since Bultz et al¹⁸ observed the usefulness of also providing information to partners, a table was set up with various relevant information and medical pamphlets at the venue for the group.

Participants attended the two-hour discussion group facilitated by a male oncology social worker experienced in conducting groups. Two partners of women who were survivors of breast cancer (ie. diagnosed a minimum of

two years ago, one pre-menopausal and one post-menopausal) were also invited as speakers. The speakers were invited to share their experiences followed by facilitated general discussion. The speakers were asked to talk at the beginning of the group to ease participants into discussions about breast cancer, as well as to exemplify open sharing of feelings and challenges.

For the purposes of evaluation, at the end of the meeting, a brief anonymous survey and a reply paid envelope was distributed to each participant. A reminder letter was also sent to all participants two weeks later. Eleven (85%) questionnaires were subsequently received. Based on the facilitator's recommendation, a follow-up session was offered to all participants four weeks after the original workshop. Only two participants attended; when contacted, other participants responded that the first workshop had been sufficient.

Measures

Since no reliable and validated quantitative instruments to assess the kind of variables this particular study sought to understand were available, a study-specific questionnaire was designed to evaluate these objectives. In the evaluation questionnaire, participants were asked to provide sociodemographic details and to respond to 17 items assessing satisfaction with the group by selecting from the five response options ranging from "strongly agree" to "strongly disagree". These items were specifically designed for the study (refer to Table 2 for the items). Scores ranging from 1

Table 2

Summary of quantitative measures of satisfaction (N=11)

ITEM	MEAN SCORE* (SD)
I believe it is important for there to be a service that would provide support for partners of women with breast cancer	4.8 (0.4)
I think the workshop was well facilitated	4.6 (0.67)
I have learned more about the emotional impact of breast cancer on partners as a result of attending the workshop	4.5 (0.52)
I would recommend the workshop to other men in my situation	4.5 (0.52)
The workshop met my expectations	4.4 (0.67)
As a result of attending the workshop, I feel more confident in supporting my partner and family in dealing with breast cancer	4.4 (0.67)
I think the venue for the workshop was appropriate	4.3 (0.47)
I think the workshop covered topics which were appropriate to partners of women with breast cancer	4.3 (0.79)
I feel less isolated as a result of attending the workshop	4.2 (0.75)
I think the length of time allowed for the workshop was appropriate	4.2 (0.87)
I feel more supported as a result of attending the workshop	4.1 (0.83)
I feel more positive about the future as a result of attending the workshop	4.1 (0.94)
I think the meeting time was appropriate	4.1(0.54)
I think the number of participants at the workshop was appropriate	4.1 (0.70)
I would prefer an on-going group instead of a one-off workshop	4.0 (0.77)
I think it was important for the workshop to be conducted by a male facilitator	3.5 (1.1)
I am intending to keep in contact with others I have met at the workshop	3.2 (0.87)

*Note. * Response options ranged from 'strongly disagree' (1) to 'strongly agree' (5).*

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("strongly disagree") to 5 ("strongly agree") were allocated, with higher scores denoting greater satisfaction. A mean satisfaction score was calculated by adding all individual scores and dividing by the total number of items. As an adjunct to these questions, the questionnaire also included four open-ended questions: (a) to identify the most useful aspects of the workshop; (b) to identify the least useful aspects of the workshop; (c) to suggest changes to improve future workshops; and (d) to suggest services that would further assist partners of women with breast cancer. Answers to these open-ended items were summarised, using open-coding by grouping similar responses into categories.

Results

Demographic information summary

Demographic data for the participants are shown in Table 1. All participants were male, aged between 36 and 77 years, with a mean age of 56.3 years. Equal numbers of participants reported having a trade (33%) or a certificate from college (33%), 22% had a bachelor's degree and 11% had a post-graduate diploma or degree. Most participants spoke English at home (89%; with the remaining 11% fluent in English) and all were married or were in a de facto relationship. The mean length of relationships was 28.9 years (ranging between 10 and 51 years). Fifty-six per cent of couples had children from their current relationships, 22% did not have children, 11% had children from previous relationships and 11% had children from both current and previous relationships.

Responses to closed-ended items

The mean score of individual satisfaction items ranged from 3.2 to 4.8 (with 3 denoting "neutral" and 4 denoting "agree"). The total mean satisfaction score was 4.2 (SD = 0.42). Table 2 provides an overview of the

mean satisfaction score for each item. The most highly endorsed item was "I believe it is important to have a service that provides support for partners of women with breast cancer" (mean = 4.8; SD = 0.40). The least highly endorsed item was "I am intending to keep in contact with others I have met at the workshop" (mean = 3.2; SD = 0.87).

Responses to open-ended items

Table 3 provides an overview of responses to open-ended questions on aspects of the workshop that participants found most useful or liked most. The most commonly identified useful aspects were the open and realistic nature of discussions by participants. Finding out how others coped and recognising that they had common concerns and were not alone were also commonly identified.

Few participants identified aspects of the workshop they did not find useful. Most commonly reported were that the workshop had been too short for everyone to talk (27%), and some contributions were anecdotal or too long (18%). Insufficient focus, others' religious views and the facilitator guiding responses were also identified as not being useful.

Finding a way to get the participants to "open up" and either allocating more time or fewer participants for the group were the two most commonly suggested improvements. Other suggestions included having more focus for the group, focusing on particular subjects such as anger and depression and having specialist presenters such as therapists and dietitians.

In identifying services to further assist partners of women with breast cancer, counselling after surgery, hospital facilitators helping partners and an ongoing group with meetings up to three times a year were some of the main suggestions by participants.

Table 3
Useful aspects of the workshop (N=11)

IDENTIFIED ASPECT	NO. OF PARTICIPANTS WHO IDENTIFIED THIS ASPECT
Open discussion	4
Realistic nature of discussion	4
Finding out how others coped	3
Recognising common concerns	3
Finding out I am not alone	3
Hearing others' stories	2
Capable facilitator	2
Full participation by all members	2
Hospital recognising the importance of partner's role in treatment of patient	1
Learning to deal with partner's feelings that she had been disfigured	1
Hearing that other couples have been brought closer together	1

Discussion

Evaluation sought to determine the effects of attending a support group on partners' sense of isolation, perceived support, future outlook, ability to support their partners and families, and their understanding of the emotional impact of breast cancer on partners. It also aimed to explore whether participants intended to keep in contact with other participants after the group, partners' views on the availability of such support, suggested improvements and what other services they believed would further assist them in dealing with their partners' breast cancer.

The mean satisfaction scores indicate that partners found attending the workshop very useful. It reduced their isolation and improved perceived support and future outlook and their ability to support their partners and families. Results also suggest that the workshop increased their understanding of the emotional impact of breast cancer on partners. The results clearly suggest that partners believe it is important to make support groups available for them. They reported that the open and realistic nature of discussions at the workshop, finding out how others coped and recognising that they were not alone and had common concerns were all useful aspects of the workshop. They identified counselling after surgery, hospital facilitators helping partners as well as the patients and having an on-going group with several meetings a year as additional services to further assist partners. While a relatively large proportion of partners indicated that they would prefer an on-going group instead of a one-off workshop, few men indicated that they intended to keep in contact with others from the group. Also, only two participants returned to the follow up session conducted four weeks later. However, this may have been due to participants only being given one week's notice about the follow-up session and also because the follow-up session was conducted too closely to the original workshop.

In response to 148 letters of invitation mailed to women with early-stage breast cancer, only 13 men (9%) responded and attended the workshop. It is unclear whether the low uptake observed is unique to Australian men, given the limited amount of literature reporting on participation rates. Bultz et al reported a 31% participation rate.¹⁸ This pilot study's accrual rate suggests that only a relatively small percentage of men are likely to attend support groups.¹⁸ However, those who chose to attend reported a high degree of satisfaction with this type of service. There are several possible reasons for this relatively low uptake. Firstly, it is possible that it reflects a low level of need for support among partners, although this seems implausible, given the large body of literature reviewed earlier that demonstrates high levels of unmet needs and psychological distress amongst partners. Given that women were contacted up to 18 months post-diagnosis, many partners might have sought support around the time of diagnosis, but may no longer require support once treatment has been completed.

Another likely explanation is that support groups may be a less than suitable strategy to meet men's information

and support needs. It has been suggested that men have difficulty talking about their emotions²⁰ and that they feel they have to give an impression of knowing everything they need to know.²¹ These characteristics represent potential barriers to help-seeking in general and attendance of support groups in particular. Also, Krizek, Roberts, Ragan, Ferrara and Lord investigated gender and cancer support group participation by comparing men diagnosed with prostate cancer with women diagnosed with breast cancer.²² It was found that men were less likely to join a support group, but men who did join attended for the same length of time as women.²² As the challenge seems to be in getting men to attend their first session, it was recommended that support groups need to be marketed differently for men, for example by referring to the group as a 'men's information group' rather than a 'support group'.²² Clearly, health services need to be responsive to men's unique needs and innovative methods, such as internet chat rooms, should be explored as potential support strategies. Future studies should assess men's unmet needs and ascertain their preferred support strategies and formats.

This study had several limitations including small sample size, lack of a control group and pre-workshop assessment. Absence of pre-workshop assessment was due to time limitations. The wide age range of participants may have impacted the effectiveness of this intervention, as partners of different ages may have differing needs; possible differences were not explored in this study due to the small sample size. In addition, no information is available about partners who declined participation, it may be that these partners differed in their level and type of support needs from partners who participated in this study. Also, no validated measures of psychological adjustment were utilised for this evaluation as *a priori* we doubted whether attending a two-hour workshop would have a significant impact on psychological variables. However, given the pilot nature of this study, future studies are now needed to evaluate similar interventions using a control group design with a larger sample size.

This study provides preliminary recommendations for a support group intervention for partners of breast cancer patients. While partners strongly identify the need for a support group, they also appear to prefer an on-going group instead of a one-off workshop. Partners reported a high level of satisfaction with the content and structure of this intervention. However, allocating more time or having fewer participants, as well as facilitating a more open discussion need to be considered for future interventions. This pilot trial is of special interest, in that it has provided preliminary evidence that support groups for partners of women with early stage breast cancer are feasible and effective in meeting partners' self-reported support needs.

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