

Supporting Blokes — providing support for male partners of women diagnosed with breast cancer

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Abstract

Background There is considerable evidence indicating poor coping strategies and increased psychological distress in the male partners of women diagnosed with breast cancer. Research suggests that the needs of male partners of women with breast cancer were not being addressed. A support group for male partners was evaluated to identify its effectiveness in addressing specific needs of those within the group.

Method A descriptive study was completed exploring the value of a male support groups. Evaluations completed after attendance at the support groups provided qualitative data.

Results The feedback received supports the premise that a formalised programme can provide male partners with the opportunity to share experiences, enhance relationships and improve coping strategies.

Conclusion The Supporting Blokes programme has the potential to be used as a template for all health care workers in providing psychosocial support to partners of women affected by cancer.

Introduction

Recent literature suggests that male partners of women diagnosed with breast cancer are at increased risk for severe depression, psychological distress and poor quality of life¹. Furthermore, the evidence indicates that the lack of support provided for partners may contribute to feelings of disempowerment and a decreased ability to cope. A male partner's health can decline during the course of the woman's care and can be negatively influenced for years after the cancer diagnosis and completion of treatment². Caregivers are the hidden patients; they provide support and guidance, attend appointments with their spouses, yet very few health professionals ask how the caregiver is doing³. The family's social support fails to acknowledge the distress of the male partner during their role as caregiver for the woman with cancer⁴. Research findings demonstrate that the male partners of women with breast cancer experienced physical and psychological symptoms including fatigue, stress, insomnia, depression, guilt, grief, isolation and, in more severe cases, substance abuse-related and affective disorders⁵. The provision of support to spouses can have the added benefit of improving overall wellbeing of both themselves and their partner⁶.

Based upon the literature, it appears that improved support provided to the male partner of a woman diagnosed with breast cancer may in turn improve the physical and psychological outcomes for both the patient and the partner⁷. In this paper, the term male partner can also be extended to include any primary male caregiver including a father or brother. More research is needed to explore support group attendance to understand the benefits and problems associated with them. This paper highlights the challenges and frustrations experienced by male partners as well as the benefits of receiving face-to-face support through regular meetings.

Background

When a woman is diagnosed with breast cancer she is often supported by a male partner who is at a high risk of increased stress and depression⁸. There is a relationship between the lack of physical, psychological and economic support given to

male partners and their reduced ability to cope⁹. Northouse *et al.*⁶ suggest that guidelines need to be developed to address the mental health and coping strategies of cancer patients' loved ones, recommending screening partners for depressive symptoms and advocates for integrating spouses in the clinical treatment of cancer.

A 13-year, longitudinal study of over 20,000 men whose partners were diagnosed with breast cancer showed a 39% increase in the likelihood of hospitalisation associated with an affective mental disorder as compared with men whose partners did not have breast cancer⁵. Further evidence suggests that the partner's social support may overlook his need for support as opposed to his role as caregiver. A study conducted by Hasson-Ohayon *et al.*⁴ showed that spouses reported more psychological distress than the patients and this may be linked with decreased social support. A review of literature on the psychological impact on the male partners when caring for a patient with cancer suggested that the support network is an important factor in reducing the distress experienced¹⁰. Further literature supports the premise that caregivers can only benefit in their role if support is directed towards them as well as the patient^{3,11,12}. Male partners have indicated that they internally struggle with the inability to process information and this had a direct impact on their ability to manage the situation¹³. Themes highlighted in a study of 15 husbands revealed that men have questions and concerns throughout the trajectory of the disease and lack of information created difficulties¹⁴. Fitch and Allard¹⁴ concluded that more support from health professionals throughout this time would be of benefit. What is important to highlight here is that male caregivers' concerns and challenges may differ from those of female caregivers¹⁴. There are gender-specific attitudes that may prevent the male partner from expressing their concerns, thereby limiting their ability to engage support¹³. Research has explored this aspect of the woman's support with limited studies on the understanding of a male caregiver's experience⁹.

In 2011 the National Breast Care Nurses' Conference was conducted in Melbourne. As part of the conference programme,

a partner panel had been organised to highlight some of the issues that both male and same-sex partners were dealing with in terms of caring for their partner's breast cancer diagnosis and treatment. The panel was facilitated by a trained psychologist and the audience consisted of breast care nurses (BCNs) and other health care providers involved in breast cancer care and support. The panel represented a demographic ranging from metropolitan and rural areas and included a woman in a same-sex relationship. One of the main themes that emerged from the panel discussion was that partners felt left out of the conversation when it came to the care and treatment of their spouses. Not knowing what questions to ask or having limited resources in terms of literature and social support made the experience for them both isolating and confusing.

Based on this information and the knowledge that no face-to-face support groups existed for male partners of women diagnosed with breast cancer in the Melbourne metropolitan region, a plan was developed to ascertain the feasibility of conducting a regular support group. This paper reveals some of the male partners' personal experiences of attending a male support group.

Method

A descriptive study was completed exploring the value of a male support group. An initial forum was organised to specifically address the needs of the male partners of women with breast cancer. Approximately 100 invitations were sent out to metropolitan BCNs and treatment centres. Of these, 20 responded, with 14 attending the opening forum held at the Living Centre in March 2011. Support groups were subsequently held quarterly and evaluated after each meeting. To date there have been nine sessions in total.

Written evaluation forms including consent were distributed at each support group. The support groups were facilitated as part of the role of the senior BCN consultant at the Think Pink Foundation — The Living Centre. Participants were informed of the evaluation aims and their participation was voluntary. Ethics clearance was included within the Think Pink Foundation — The Living Centre evaluation of programmes. The BCN was trained in group management and ongoing support. Meetings were co-facilitated by health professionals who were able to respond appropriately and provide support and acknowledgement. Those requiring additional support were referred back to their general practitioner. Follow-up calls were made by the BCN when any issues around distress or group dynamics were identified.

Initial forum results

From the initial forum, nine of 14 (64%) responded to the evaluation and all indicated the desire for ongoing meetings. The evaluation contained a needs analysis to determine interest in future meetings and frequency. One hundred per cent indicated the desire for future meetings during the week in the evening, with 77% preferring the frequency to quarterly as opposed to bimonthly (22.2%). None of the respondents were interested in the monthly option.

The main points raised in the qualitative data from the initial forum included: lack of support; poor social networks; limited literature for partners; communication difficulties and managing circumstances under stressful conditions. The male partners

cited the opportunity to mingle informally with other men experiencing similar circumstances and to be able to meet and listen to a health professional (BCN) who could identify common themes that male partners were experiencing.

Support group 2011 to present

Since the initial forum held in March 2011 there have been nine meetings (participants n=80). Attendance has been consistent with numbers averaging eight for each meeting (range from 14 to 3). Whilst each meeting attracted new members, there was a core group of four men who attended most meetings.

Evaluations were sent electronically the day following each meeting with an average response rate of 60%. The evaluation forms included age, residential area, highlights of the meeting, stage of partner's diagnosis, referral source and what prompted them to attend. There was also the opportunity to comment on guest speakers, topics and recommendations for future meetings. See Appendix 1 for the evaluation form.

Support group participants over the two-year period 2011–2013 were aged between 28 and 73 years with all age groups evenly represented. Participants were mainly from the Melbourne metropolitan region. Neither age nor place of residence appeared to influence attendance rates, with all verbalising similar experiences and challenges across the trajectory of their partner's breast cancer journey. All spoke English as their main language.

The guest speaker was identified by 62% as a highlight, whilst 100% valued the addition of guest speakers at the meetings. To date there have been five guest speakers including a psychologist, breast surgeon, social worker, support group coordinator from the Victorian Cancer Council and relationship counsellor from Relationships Australia.

The evaluations also asked which category best described their partner's stage of diagnosis. The categories included recently diagnosed and currently receiving treatment, recently completed treatment (within six months), completed treatment six months or more and diagnosed with secondary breast cancer. Most of the participants (83%) indicated that their partner had recently completed treatment whilst the remaining participants were evenly distributed between the other categories. Of all the meetings, there were only two male partners whose wives had secondary breast cancer; however, they continued to attend meetings sporadically over the two-year period, dependent on how they were coping and what level of support they needed.

Qualitative results

Having the support groups on a quarterly basis meant that the stage of their partner's diagnosis and treatment was constantly changing and evolving. The regular attendees described the meetings as "helping them throughout the course of their partner's breast cancer journey no matter what the stage".

All of the participants said that meeting other males in similar circumstances was the highlight. This was evident in the support groups where a rapport was quickly established between the members, regardless of their age or stage of their partner's diagnosis and treatment. One male partner whose wife had advanced breast cancer felt that the group was of great benefit as it gave him the opportunity to express his grief and at times

his anger in a safe and supportive environment. Other members were followed up with a phone call the next day to ascertain whether having men whose partners had advanced disease in the group was “too confronting”. The response indicated that all were pleased to be able to support one another, regardless of stage of the breast cancer.

When asked the question as to what prompted the men to attend the meeting, 75% responded equally with the reasons to receive support and information and also meet other males. The participants (80%) found out about the sessions through their partners or the information flyers. It appeared that the motivation to attend was based on the peer support they needed rather than the need to please their partner. As one participant said:

It was great to share our experiences, confusion, learning and questions with an interested group. I felt a sense of relief through sharing my thoughts on the night which up until now have been hidden from family and friends ... us blokes are supposed to be the tough ones!

Some partners felt the need for support at the beginning of treatment whilst others felt most benefit at the conclusion of treatment when they felt disillusioned as to why life had not returned to the way it was prior to the diagnosis. Simultaneously, they verbalised that their partners also experienced a high level of anxiety at the completion of treatment associated with fear of recurrence and chronic fatigue. The repercussions of these frustrations influenced their relationship with communication and intimacy noted as a major challenge. The partners indicated that the meetings allowed them to normalise these feelings by speaking with other male partners who were experiencing similarities.

It was good to be able to talk about concerns I was keeping to myself so as not to upset my wife and get support from other carers dealing or having dealt with similar issues.

For another whose wife was still having treatment:

For me, the next meeting will be around the time my wife starts her radiation treatment, so it will help me to tap into the other's experiences.

These comments highlight the importance of shared experiences, in which each participant could relate to another. The men discussed how dealing with their emotions associated with their partner's breast cancer was a personal experience and that they did not feel comfortable sharing these feelings with outside friends or work colleagues. It was not uncommon to hear within the meetings that it was a great relief to know other male partners were feeling similar frustrations and this created a safe environment in which to share honestly and openly within the group.

The impact of the meetings for their partners was also evident with some positive verbal feedback indicating improved communication and understanding between the couple as a result of the guest speaker's information and the sharing of experiences. One woman phoned following a meeting and said she had felt relieved when her partner had attended because he met other blokes whose wives suffered “chemo brain”. He had thought it was just a term that she had made up to get away with everyday forgetfulness. He discovered through the meetings that

this was a condition that many of the men had experienced with their partners so was, therefore, able to be more empathetic to her concerns.

For others, the meetings have been a short-term solution for those initially experiencing difficulties in their relationships. One partner indicated that the initial meetings assisted greatly with issues around communication with his wife. He explained to the group that he never knew what to say or how to react to his wife's diagnosis but since attending the meetings, it had opened up the channels of communication for both of them and, therefore, improved their relationship considerably.

Discussion

The purpose of the current evaluation was to provide information on the male partners' experience and expectations of a partner support group. The support groups, which were facilitated by a BCN, provided a supportive environment for the male partners to share their experience. The evaluation identified that male partners wanted to share their experience with other males in a safe environment and the face-to-face meeting provided a supportive group.

The development of a specific support group to meet the needs of male partners was identified in the first forum and the continued attendance of the males at the support group highlighted the benefits of this type of group. The evaluation identified that meeting of other males with similar difficulties helped them to understand and express their own grief and anxiety.

One of the challenges that facilitators face with any group is sustainability¹⁵. Historically, a face-to-face group particularly for men appears to have a short life span, with interest in attending gradually subsiding. This may be due to repetition of information. The current group had new members and a core number of males who attended each meeting. Feedback from this evaluation indicated that guest speakers and a variety of topics led to sustained interest in attending. Some members actually verbalised their disappointment if they are unable to attend. Conducting the meetings on a quarterly basis was noted to maintain interest as varying stages of diagnosis and treatment bring with it new challenges.

The environment was important for the participants as it was a non-threatening, supportive group. Research has noted that the support groups are likely to be beneficial if the participants are linked by previous experience and match the learning styles of the individual¹⁶. The actual meeting place and connections influences the participants' anxiety, thus a non-clinical meeting area tends to have fewer negative connections for the participants¹⁵. Feedback also indicated that meeting in a centrally located, non-clinical environment was both non-threatening and conducive to feeling relaxed. As the participants arrive, light refreshments are served and this time gives regular and new members a chance to mingle and introduce each other. Previous research has identified that the setting and culture of the support group influences the participants' attendance¹⁵. The main reasons noted for continued attendance of the support group were having a feeling of connectedness to group, sense of community, hearing current medical information and good group leadership^{15,17}.

Another challenge that group facilitators can face is that of dominating members in the group. At times support groups can be dominated by members sharing their opinions. Facilitators can find it difficult to ascertain the most effective way of dealing with this scenario and efforts to close the conversation can be met with resistance. Reflection on group dynamics after each meeting can ensure flow and sharing between members¹⁷. Possible solutions to promote good group dynamics are to avoid open questions directed at particular members, limit introduction time and using name badges¹⁷. Other strategies include limiting the size of the group, with eight being noted as an optimal size and being aware of group dynamics to ensure all members of the group are included and supported¹⁷. Specific training in group facilitation has been identified as beneficial to allow a clear flow of information while not allowing group members to dominate the conversations¹⁸.

One of the benefits of ongoing attendance at support groups is the building of information for the participants as they move along the trajectory of breast cancer. Butow *et al.*¹⁵ noted that a support group which changes as the requirements of the participants change is more likely to have continued attendance than one which provided static information. One of the aims of the male support group was to provide not only information but useful contacts for the supporting male partners. The group facilitator was a senior BCN who was able to provide specific contact to BCNs who were able to inform and direct during the different stages of their partner's breast cancer journey.

The use of guest speakers who represented a range of professions was noted as an important feature and reason for continued attendance at the support groups. The guest speakers' expertise included supportive care after a traumatic experience, general cancer care, and psychosocial care to strategies for developing good coping mechanics. The guest speakers provided the men with information for their personal journey and new strategies to manage stress. Previous research has noted that most carers are aware of support groups but do not access them as they do not think that the information obtained from the group will help their journey¹⁹. The use of regular evaluation of the participants' needs and trajectory of breast cancer assisted the facilitation of appropriate guest speakers to maintain attendance.

The development of specific male support groups provided a safe environment for the male support people to have face-to-face contact in a facilitated group. The group allowed for support between members but also provided information and guidance as needed. The evaluation ensured ongoing needs of the support group were met. This provision of support has been found to benefit the male partners as opposed to one-on-one support with health professionals, phone support or online support. The facilitation of the group by a BCN ensured group dynamics and specific support needs were met.

Recommendations

The male partners' group can be used as a template for all tumour streams and not exclusively for partners of breast cancer. Furthermore, the success of the Supporting Blokes meetings raises the issue of support for other partners affected by a cancer diagnosis, including those in same-sex relationships. The face-to-face meeting enabled an open sharing of concerns.

The facilitated groups allowed for conversation and exchange of ideas and experiences between partners in safe environment.

Conclusion

The Supporting Blokes meetings continue to provide support for male partners of women diagnosed with breast cancer. Numbers remain consistent, with both regular and new members attending each quarter. Guest speakers are organised in response to identified needs of the members. Responding to feedback and requests ensures that the meetings continue to stimulate and engage the participants in discussing both personal concerns and those that affect the group as a whole.

Whilst social networking and online services have become a popular way of connecting, face-to-face support appears to provide a stimulating yet safe environment to share personal stories and learn from other's experiences.

Limitations

This paper presents an evaluation of partner support group meetings. The findings are related to these meetings and may not be able to be generalised. However, the information may provide guidelines for future research exploring the partner's needs when supporting a woman with breast cancer.

References

- Ganz PA, Kwan L, Stanton AL *et al.* Quality of Life at the End of Primary Treatment of Breast Cancer: First Results From the Moving Beyond Cancer Randomized Trial. *J Natl Cancer Inst* 2004; 96(5):376–387. DOI: 10.1093/jnci/djh060.
- Baucum DH, Porter LS, Kirby JS *et al.* A couple-based intervention for female breast cancer. *Psychooncology* 2009; 18(3):276–283. DOI: 10.1002/pon.1395.
- Coyne E, Wollin J & Creedy D. Exploration of the family's role and strengths after a young woman is diagnosed with breast cancer: Views of the women and their families. *Eur J Oncol Nurs* 2012; 16(2):124–30. DOI: 10.1016/j.ejon.2011.04.013.
- Hasson-Ohayon I, Goldzweig G, Braun M & Galinsky D. Women with advanced breast cancer and their spouses: diversity of support and psychological distress. *Psychooncology* 2010; 19(1):195–204. DOI: 10.1002/pon.1678.
- Nakaya N, Saito-Nakaya K, Bidstrup PE *et al.* Increased risk of severe depression in male partners of women with breast cancer. *Cancer* 2010; 116(23):5527–34. DOI: 10.1002/cncr.25534.
- Northouse L. Helping patients and their family caregivers cope with cancer. *Oncol Nurs Forum* 2012; 39(5):500–6. DOI: 10.1188/12.ONF.500–506.
- Northouse L. Helping families of patients with cancer. *Oncol Nurs Forum* 2005; 32(4):743–50. DOI: 10.1188/05.ONF.743–750.
- Feldman B & Broussard CA. Men's Adjustment to Their Partners' Breast Cancer: A Dyadic Coping Perspective. *Health & Social Work* 2006; 31(2):117–27.
- Cochrane BB & Lewis FM. Partner's adjustment to breast cancer: a critical analysis of intervention studies. *Health Psychology* 2005; 24(3):327–332. DOI: 10.1037/0278-6133.24.3.327.
- Pitceathly C & Maguire P. The psychological impact of cancer on patients' partners and other key relatives: a review. *Eur J Cancer* 2003; 39(11):1517–1524. DOI: org/10.1016/S0959-8049(03)00309-5.
- Scott JL, Halford WK & Ward BG. United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynaecological cancer. *J Consult Clin Psychol* 2004; 72(6):1122–1135.
- Edwards B & Clarke V. The psychological impact of a cancer diagnosis on families: the influence of family functioning and patients' illness characteristics on depression and anxiety. *Psychooncology* 2004; 13(8):562–76. DOI: 10.1002/pon.773.
- Forrest G, Plumb C, Ziebland S & Stein A. Breast cancer in young families: a qualitative interview study of father and their role and communication with their children following the diagnosis of maternal breast cancer *Psychooncology* 2009; 18(1):96–103. DOI: 10.1002/pon.1387.
- Fitch MI & Allard M. Perspectives of husbands of women with breast cancer: impact and response. *Cancer Oncol Nurse J* 2007; 17(2):66–78.
- Butow PL, Kirsten TJ, Ussher MG *et al.* What is the ideal support group? Views of Australian people with cancer and their carers. *Psychooncology* 2007; 16(3):1039–1045. DOI: 10.1002/pon.1172.
- Connell S, Patterson C & Newman B. Issues and concerns of young Australian women with breast cancer. *Support Care Cancer* 2006; 14(5):419–26.
- Weis J. Support groups for cancer patients. *Support Care Cancer* 2003; 11:763–768. DOI: 10.1007/s00520-003-0536-7.
- Coward D. Facilitation of self-transcendence in a breast cancer support group *Oncol Nurs Forum* 2003; 30(2):291–298.
- Steginga SK, Campbell A, Ferguson M *et al.* Socio-demographic, psychosocial and attitudinal predictors of help seeking after cancer diagnosis. *Psychooncology* 2008; 17(10):997–1005. DOI: 10.1002/pon.1317.