**Psycho-Oncology**
*Psycho-Oncology* **23**: 956–958 (2014)
Published online 2 April 2014 in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.3519

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# Male breast cancer networking and telephone support group: a model for supporting a unique population

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Received: 30 September 2013
Revised: 14 February 2014
Accepted: 24 February 2014

Dear Editor,

## Introduction

Breast cancer is diagnosed in 2000 men and nearly 200,000 women in the USA annually [1]. Ninety-nine percent of breast cancers are diagnosed in women in this country, so the clinical, research, and advocacy efforts around breast cancer have been primarily focused on women [2]. Treatment decisions for men are extrapolated from data in women because there has never been a successful randomized clinical trial that studied male breast cancer specifically, mostly due to the comparative rarity of male patients. Even large referral centers in the USA usually see fewer than 50 male patients with new breast cancers annually. Pink ribbons and T-shirts have successfully increased breast cancer awareness and helped to raise money for breast cancer research, but also serve as visual reminders that breast cancer is seen as a women's disease. The strong association between breast cancer and female gender may cause distress for men with the disease. Furthermore, aspects of their clinical care such as questionnaires asking about menstrual functioning and clinical trials that exclude males may heighten these feelings. Online or in-clinic educational materials about management of breast cancer treatment side effects (e.g., vaginal dryness) may not be applicable to them. An online survey of 42 male breast cancer survivors revealed inferior quality of life scores in the participating male breast cancer survivors than would have been expected in the general population of men [3]. Both hot flashes and sexual dysfunction were also noted as common in this population. Optimal symptom management strategies are uncertain, and it can be difficult for men to find other male patients who can advise them on what to expect during and after breast cancer treatment.

### Group structure and participation

Due to the relatively low prevalence of male breast cancer, it could be difficult to recruit enough men to attend an in-person support group [4]. In an effort to make our support group more accessible, we elected to host a male breast cancer telephone support group. For this group, we provided a toll free number and access code to enable participants to be connected with the entire group simultaneously, similar to a conference call. Out of concern that many male patients might work during the day, we decided to host the group during the noon lunch hour. Two months before the telephone support group met for the first time, we widely distributed flyers in the breast oncology center clinic encouraging interested male patients to call for information about the group. We sent targeted letters to male breast cancer patients who had been seen in clinic at least two times in the preceding year, and we solicited direct referrals from breast oncologists via e-mail. Eleven patients called for information, and all 11 participated in at least one of the six monthly group sessions. In fact, all 11 members continued throughout the 6 months with the occasional absence due to scheduling conflicts. After the group began, we received calls from five additional men who were interested in participating in the group; they were placed on a waiting list and assured they could participate in the next group. A single dedicated social worker who was interested in caring for this population facilitated all support group calls. This social worker was experienced in facilitating support groups for breast cancer patients. These included five telephone groups for young women with newly diagnosed cancer, two in person groups focused on stress management interventions, and one telephone group for young women with metastatic breast cancer. The social worker's role on the male breast cancer group calls was the following: (1) to

engage the members in discussion about their shared concerns; (2) to ensure that the sessions were focused and productive; and (3) to guide the group in the successful development of a sustainable long-term network. On each call, the participants determined the agenda for the next session based on their concerns. Topics included sexual health, feelings of isolation, educating friends and family members about male breast cancer, treatment side effects, and how to cope with the emotional impact of living with a disease that is associated with women. The men discussed common frustrations including the lack of resources (both supportive and educational) available for men and loss of libido. A sexual health expert participated in one of the calls to address concerns about sexual dysfunction that had been raised by participants during a prior call. A medical oncologist joined another call to answer questions about treatment side effects, new research findings (e.g., data supporting the use of 10 rather than 5 years of tamoxifen), alternative medicines (e.g., Chinese herbs), and opportunities for research participation. Six months after the last meeting of the support group, participants were asked to complete an anonymous Web-based survey as feedback for the group organizers. Eight of eleven participants (72%) returned the survey, and three quarters of respondents reported that the group was 'helpful' or 'very helpful', expressing appreciation for the following aspects: getting information (75%), meeting others in a similar situation (75%), having a forum for sharing thoughts and feelings (62.5%), finding mutual support and understanding (62.5%), feeling less alone (37.5%), and having the chance to hear from staff or other presenters (25%). Nearly 90% reported the following: (1) that they would recommend the group to other men coping with breast cancer; and (2) that the goals they had in mind when they elected to participate in the group were achieved and/or exceeded.

## Discussion

Ideally, a telephone support group should be relatively small (from six to eight participants) to allow members enough opportunities to share [5]. Nonverbal communication is not accessible in a telephone group, so it can be difficult to ensure adequate 'talk time' for all of the members if there are too many. In this instance, given the paucity of alternative sources of support for this population, we elected to allow all of the men who were initially screened and interested to join the group. The lack of attrition (typically at least a few participants drop out of any support group) suggests a strong commitment among the members to connect with one another in this way.

Surprisingly, there are few previous reports on the utility of telephone support groups in a cancer patient population [6]. There have been some studies on group therapy for cancer patients using a hybrid model consisting of both in-person and telephone support. One study found that using this hybrid model for women with metastatic breast cancer in rural Australia led to a reduction in negative affect as well as a reduction in intrusive and avoidant stress symptoms [7]. Studies on telephone support groups with no in-person component were more difficult to find and, the most recent, was completed in 2001. There were several studies conducted between 1982 and 2001 that examined the utility of telephone support groups in other populations such as persons with hemophilia and HIV/AIDS [8]. The participants in the study of people with HIV/AIDS reported that they benefited from being able to share information, and the group also decreased their feelings of isolation and loneliness [8]. There are some data that suggest that using the telephone as a modality for group support results in increased participation as well as more rapid development of group cohesion [5]. The anonymity of the phone can sometimes accelerate the process of building trust. In this pilot male breast cancer support group, the participants were open about some very difficult topics (such as sexual dysfunction and depressed mood) as early as the second call. However, it is uncertain whether this strong group cohesion resulted from the telephone modality or would have also occurred during an in-person group of these participants. We are now attempting to provide support to male breast cancer patients nationally by creating an online Male Breast Cancer Community in partnership with CancerConnect, a platform of Web-based communities for cancer patients and their loved ones, to facilitate support and communication within this unique population. Online support communities have proven successful in other groups of male cancer patients including those with prostate cancer [9]. In the future, we may explore use of Web-conferencing (possibly using Skype) or social networking (e.g., Google+ or Facebook) to better serve male patients' needs. Still, it is possible that some male breast cancer patients (possibly including those who are less computer-savvy and/or those who have less reliable Internet connections at home) may prefer telephone-based support.

## Conclusion

To our knowledge, this was the first support group that was specifically designed for men with breast cancer. Eleven men participated in a telephone group consisting of six monthly hour-long calls with no attrition. The success of this pilot intervention suggests that a similar modality could be useful for patients with other rare diseases or in circumstances where supportive resources may be particularly limited.



**DOI**: 10.1002/pon

**Key points**

- Breast cancer may have substantial and unique psychosocial impacts on male patients.
- Men with breast cancer may face a number of barriers to accessing psychosocial support.
- Only 1% of all breast cancers occur in men, and most emotional supports are geared toward women, so the unique needs of male patients are underappreciated and often ignored.
- In an effort to address these needs, we developed a pilot support group for men with breast cancer.
- Based on the success of this group, we have now created an online Male Breast Cancer Community in partnership with CancerConnect, a platform of Web-based communities for cancer patients and their loved ones, to facilitate support and communication within this unique population on a national level.

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**DOI**: 10.1002/pon