Gender and Cancer Support Group Participation

PURPOSE: Although support groups are offered to many patients who have received a diagnosis of cancer, a majority of patients choose not to participate. This article reports the results of a study comparing the behavior of men diagnosed with prostate cancer and women diagnosed with breast cancer in their responses to invitations to participate in support groups.

DESCRIPTION OF STUDY: One hundred thirty women with breast cancer and 87 men with prostate cancer completed a structured telephone interview. The interview included questions about the patients’ choices about support group participation.

RESULTS: Interview findings showed that men are less likely to join a support group, but those men who do join attend meetings for about 1 year, as do the women who join. Men and women cite essentially the same reasons for participation: to learn more about their diagnosis, to share their concerns, and to compare their physical and emotional progress with other individuals.

CLINICAL IMPLICATIONS: These results indicate the need for further exploration of effective interventions for men and women who have been diagnosed with prostate and breast cancer, respectively, in an effort to offer support for the difficult psychological and emotional issues associated with their diagnoses. Although more women than men join support groups, the majority of both populations (67% for women, 87% for men) do not attend any support group meetings. Innovative approaches are needed to encourage participation in existing support groups or to design alternative interventions.

KEY TERMS: Breast cancer; Gender; Prostate cancer; Psychosocial support; Support group

Support groups for patients with cancer have long been offered, and are usually organized and led by oncology social workers, nurses, psychologists, or physicians. Given the anxiety and fear that accompany a diagnosis of cancer, it is understandable that people seek psychosocial support from professionals and from those who share their diagnosis, a situation that is unique to support groups. It is generally agreed that people who attend find the groups helpful. However, although support groups have become widely available, most patients who are offered this intervention do not attend. It is, therefore, important for clinicians to know who joins support groups, who does not join, and why.

Literature Review

A cancer diagnosis is devastating for men and women. Although lung cancer remains the leading cause of death from cancer for both men and women,1 the total number of persons diagnosed with either breast cancer or prostate cancer exceeds the number diagnosed with lung cancer.1 Prostate cancer took the lives of an estimated 39,200 men, and breast cancer took the lives of 43,900 women in 1998.1 Aside from the impact on the population, these two types of cancer carry particularly devastating significance for the women and men involved.

A diagnosis of breast cancer, with its potential for mor-
bidity and disfigurement, is an extremely stressful event in the life of a woman.\textsuperscript{2,3} She must undergo breast surgery and possibly radiation treatment and chemotherapy. Although few women with breast cancer develop a psychopathology that warrants psychiatric treatment, many experience some psychological distress\textsuperscript{4} and mild mood disturbance.\textsuperscript{5} The woman with cancer may become isolated and lonely, and may experience diminished social activity. Her sexual and other intimate relationships may be threatened. Psychosocial intervention at an early stage of diagnosis and treatment is often recommended.\textsuperscript{2,6}

Men diagnosed and treated for prostate cancer suffer difficult physical and emotional life changes. The side effects of treatment may include the loss of sexual desire and function, and urinary incontinence.\textsuperscript{7–9} Litwin et al\textsuperscript{10} reported that these complications from treatment are more prevalent than previously believed. Although there are many articles discussing the psychological, social, and physical changes that women experience as a result of breast cancer, less is written about these aspects of men’s experience after treatment for prostate cancer.\textsuperscript{11}

Support groups are widely used as a psychosocial intervention for cancer.\textsuperscript{12–15} Although some studies suggest the intervention’s effectiveness in improving survival,\textsuperscript{16} the vast majority of studies indicate the effectiveness of support groups for mitigating the psychosocial aspects of cancer by conveying information, empowering patients, enhancing or facilitating social and psychological adjustment, and helping patients cope with life after a diagnosis of cancer.\textsuperscript{17–21} Enhancing the adjustment to a knowledge of terminal illness has also been effectively addressed in a group support setting.\textsuperscript{20}

Despite the proliferation of reports on support groups and their effectiveness, few articles describe the characteristics of those patients who decide to participate. Further, few studies have focused on participation in gender-related, disease-specific support groups such as those for breast cancer patients or the more recently formed support groups for prostate cancer patients.

Bauman et al\textsuperscript{22} studied the participation of 154 cancer patients in two open-ended, professionally facilitated support groups, one for patients with leukemia, and one for patients with lymphoma. These authors found that patients who had sought help from other mental health professionals were more likely to attend support group meetings than those who had not, and that these patients continued to exhibit help-seeking behavior in and out of the group. A patient’s disclosure to one or more friends at the time of diagnosis was unrelated to later participation in the support group. Well-educated patients were more likely to attend support groups than less educated patients, though low income was not a predictor for nonattendance. Geographic distance from the hospital was no barrier to attendance. The authors determined that “the most powerful theme running through the interviews with participants was the importance of seeing and talking with other patients.”\textsuperscript{22}

Taylor et al\textsuperscript{23} studied a sample of 667 cancer patients, some of whom had participated in support groups and some of whom had not. Breast cancer patients represented 45% of the study sample, and all kinds and stages of cancer were included. The authors compared the responses of attenders to those of nonattenders on a number of variables. The subjects’ characterization of the support of family and friends as inadequate was related, but not to a significant degree, to participation in the group. Negative experience with a member of the medical community, however, was positively related to the choice to participate. Attenders were as likely as nonattenders to discuss cancer issues with family and friends, and to report these interactions as helpful.\textsuperscript{25} The authors note that support groups in this study, and in others cited by the researchers, appear to appeal to middle-class white women, women who also make use of the more traditional mental health resources. The authors found that support groups are disproportionately underused by certain groups—men generally, minority members, and persons of low socioeconomic status. This caused the authors to question whether the cancer support group may be redundant, drawing individuals whose mental health needs are already likely to be met, while failing to attract the very individuals whose needs are not met by traditional mental health services.\textsuperscript{25}

Support Groups for Breast Cancer

Support groups for breast cancer vary in composition and method but generally consist of small groups of women whose focus is on coping and adaptation to the physical, emotional, and psychological changes caused by their illness.\textsuperscript{20,24–26} Some groups include women with metastatic cancer and address the fears associated with terminal illness.\textsuperscript{20} Others are designed for women with primary breast cancer and are time limited with a supportive-expressive orientation.\textsuperscript{24} Such groups are characterized by voluntary participation and provision of emotional support.\textsuperscript{25} In an earlier, but unpublished study, Taylor et al\textsuperscript{25} reported that, “only 10% of breast cancer patients from a private practice had attended cancer support groups, and most of these patients had dropped out because the groups did not meet their needs.”

Support Groups for Prostate Cancer

Support groups for men with prostate cancer are now offered by two national organizations. The American Cancer Society offers \textit{Man to Man}, and the National Foundation for Urologic Disease offers \textit{Us Too}. Social workers report that patients with prostate cancer respond favorably to the psychoeducational models typically adopted by these organizations.\textsuperscript{27–29} For example, Calabrese\textsuperscript{27} described monthly meetings that present information on topics suggested by the patients. These topics consist of 1) information and research studies about prostate cancer and treatment options and 2) information on maintaining the best possible quality of life. Kules and Axelrod\textsuperscript{28} have led monthly groups that begin with lectures and are followed by meetings of smaller subgroups of patients who share similar concerns. Patients are grouped according to their stage of disease, and the discussion is centered on coping strategies for dealing with treatment side effects. Separate groups are offered to significant others.
Feldman adopted a nontraditional approach for men with prostate cancer and their families. His study at the National Institutes of Health involved many patients who were far from home. Feldman theorized that the needs of older men with prostate cancer might differ from those of members of traditional support groups. Accordingly, he established the Suramin Club, a group facilitated by physicians, nurses, and social workers that included recreational activities as part of its meetings to better serve the needs of this population. Special efforts were made to ensure that patients were aware of the weekly meetings, and that informational speakers and recreational trips were planned. The author reports that this “nontraditional” support group was rated favorably by its members. Interestingly, the recreational trips received the highest ratings, and two informational meetings in which physicians discussed prostate cancer or its treatment received the second highest ratings. These findings led Feldman to conclude that the opportunity for patients and families to meet in an informal environment may be more important than formal program content.

As shown by these studies, understanding the reasons that persons become participants in support groups is important in designing effective models and in targeting those persons who can benefit from participation. The current study was undertaken in a regional cancer center in which large numbers of persons with breast and prostate cancer are treated. Support groups for these patients are accessible throughout the region, allowing the opportunity to survey patients with breast or prostate cancer about their group participation and to make gender-related comparisons.

Methods

Research Questions

A group comparison study design was used to compare women who had been diagnosed with breast cancer with men who had been diagnosed with prostate cancer. In conducting this study, the questions to which the authors sought answers were: 1) Do women who have been diagnosed with breast cancer and men who have been diagnosed with prostate cancer differ from each other in their patterns of support group participation? 2) Do women and men differ in their reasons for joining cancer support groups?

Subjects

Subjects were selected from surviving patients who had been treated at H. Lee Moffitt Cancer Center in Tampa, Florida, for breast or prostate cancer between January 1, 1993, and June 30, 1996. Patients from out of state were excluded as were patients diagnosed with stage IV disease because of the potential difficulty in completing the survey. Initially, subjects were drawn from the patient list through a systematic sampling of every other case. A letter of introduction describing the study and inviting their participation was sent to 136 prostate and 259 breast patients. Thirty-five percent (n = 47) of the prostate patients and 41% (n = 106) of the breast patients could not be reached by mail (ie, the letter was returned) or by a follow-up phone contact. Each potential subject was called on at least three occasions at different times of day. This left 89 prostate cancer patients and 153 breast cancer patients who were contacted. Of this number, 89% of the prostate cancer patients (N = 79) and 81% of the breast cancer patients (N = 124) agreed to participate.

A second, supplementary collection of data was implemented when it was learned that only 10 of the 79 prostate cancer patients had attended a support group. Therefore, men attending a Man to Man meeting and women attending a breast cancer support group were asked to participate in this study. About 80% of those present, most of whom were patients at H. Lee Moffitt Cancer Center, agreed to participate. This purposive sampling method increased the number of attendees whose responses and support group behavior could be analyzed. The data collected from these subjects were coded in a way that would allow the investigators to separate the data collected from the supplementary sample and from the first systematic sample. The total number of subjects included 87 men and 130 women.

Although the potential existed for a subject to be deselected in the systematic sample and later recruited in the purposive sample, a review of accrued subjects revealed that none were included in both samples. Finally, no men with breast cancer were subjects in this study.

Procedures

The systematically selected patients were sent a letter signed by their own doctors and by the principal investigators requesting their participation in a research project on cancer support groups. The letter informed the subjects of the research to be done, assured the patients first, that their participation would not influence their treatment at the cancer center, and second, that their participation and responses would be treated confidentially. These subjects were then contacted by phone by students enrolled in a Master’s of Social Work (MSW) program. All interviewers were trained by the investigators in the use of a standardized interview format, which had been pretested and revised accordingly for clarity.

Approval for the study was obtained from the university’s Institutional Review Board before patient selection. There were no clinical interventions involved in this study, and accordingly, no further written or formal informed consent document or process was required. Data were treated confidentially. Once the patients agreed to participate, a telephone or face-to-face interview was completed by one of the MSW students.

Instruments

The interview was based on a standardized interview protocol that began with demographic questions. Using standard memory prompts, the interviewer then requested
information concerning what the participants remembered about their initial visits to the cancer center and whether they were told about support groups. Finally, they were asked about their own involvement in support groups. They were queried about participation in support groups sponsored by the cancer center as well as groups available in the community such as *Man to Man* and *Reach to Recovery*.

Participants of support groups were then asked to rate the relative importance of three reasons for attending, using those offered by Bauman et al.22: 1) The group would provide the opportunity to compare my emotional and physical progress with that of other patients; 2) the group would provide the opportunity to learn more about breast (prostate) cancer; and 3) the group would provide the opportunity to share my concerns with other breast (prostate) cancer patients. They were also asked how many meetings they attended over what period of months.

**Data Analysis**

A comparison of the percentages of men and women who joined support groups was performed to determine the difference in participation by men with prostate cancer and women with breast cancer. A *t* test analysis was performed to determine whether men or women attended more meetings, or whether either attended meetings over a longer period. Finally, chi-square analysis was done to compare the men and women patients who had joined a support group (attendees) as to the reasons that they thought were important in their decision to join.

**Findings**

**Demographics**

Demographic characteristics of the sample studied included 87 men with a mean age of 69 years. Most (87%) were married, 89% were white, and 77% had some college education. The 130 women had a mean age of 60 years. Eighty-six percent were white, 72% were married, and 64% reported some college education.

**Attendance Behavior**

Were women or men more likely to attend support groups? When attendance of support groups was compared, only those subjects that were part of the original systematic sample (the 124 breast cancer patients and 79 prostate cancer patients from the pool of eligible patients at H. Lee Moffitt Cancer Center) were used. Excluded from this calculation were those subjects who were recruited through visits to community support groups.

Before analyzing the prevalence of support group attendance among the patients with breast or prostate cancer, the investigators examined patient responses to the question: Were you told about support groups? Seventy-one percent of the breast cancer patients and 56% of the prostate cancer patients were aware of the support groups. In comparing the actual participation, women were more likely than were men to attend at least a single support group meeting. Thirty-three percent of women (n = 41) attended at least one support group meeting. Only 13% of men (n = 10) attended at least one support group.

The authors then compared attendance rates among those subjects who recalled being told about support groups. Thirty-five percent of women and 24% of men who were aware of groups attended. Unknown is the extent to which the subjects’ failure to remember being told about the support group was an indication of disinterest or a perception of having no need of support.

At this point in the data analysis the supplementary sample of attenders was added before comparing attenders to nonattenders. In exploring age as a factor for attendance, findings showed that the average age of attenders was 59.5 years (SD = 13.5), while that of nonattenders was 65.2 years (SD = 10.8). This difference was statistically significant (*P* = .005). We then did a separate analysis for each gender. The average age of breast cancer attenders was 55.8 years (SD = 13.9) compared to 61.9 years (SD = 11.9) for nonattenders (*P* = .012). The average age of prostate attenders was 67.7 years (SD = 8.1) compared to 69.6 years (SD = 6.9) for nonattenders (*P* = .332, which is not significant).

For those attending support groups, the attendance patterns of men and women were comparable. Women attended an average of 10 meetings, and men attended an average of 10.6 meetings (Table 1). The majority of subjects participated in five or fewer meetings. At the same time, one fourth of subjects attended more than 10 meetings. It should be pointed out that subjects were asked to estimate the number of meetings they attended. Actual attendance records were not available.

Finally, there was little difference between men and women in the period of time over which the meetings were attended. Women stated that they attended meetings over an average of 11.8 months, and men over an average of 15.2 months, which is not a significant difference.

**Reasons for Decisions to Attend**

Did men and women cite different reasons for their decision to attend a support group? Attendees were asked

<table>
<thead>
<tr>
<th>Number of Meetings Attended</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1–2</td>
<td>15</td>
<td>24.2</td>
</tr>
<tr>
<td>3–5</td>
<td>21</td>
<td>34.4</td>
</tr>
<tr>
<td>6–10</td>
<td>9</td>
<td>14.8</td>
</tr>
<tr>
<td>11–16</td>
<td>8</td>
<td>13.1</td>
</tr>
<tr>
<td>17 or more</td>
<td>8</td>
<td>13.1</td>
</tr>
<tr>
<td>Total</td>
<td>61</td>
<td></td>
</tr>
</tbody>
</table>

*Original sample of 51 plus purposive sample of 14, total N = 65.
†No response from four subjects in the total sample.
to identify whether the three aforementioned reasons for attending a group were “not important,” “somewhat important,” or “very important” in their own decisions to attend a support group.

In attempting statistical comparison, it was found that only a few patients described any reason as “not important,” which resulted in inadequate cell sizes. Therefore, the “not important” and “somewhat important” responses were combined. Chi-square analyses were performed (Table 2). There were no significant differences between men and women as to how important it was to share concerns with other cancer patients and to compare their progress. The data suggest that men may be more likely than women to attend a support group to learn more about their cancer diagnosis, as this chi-square value approaches statistical significance \( P = .07 \).

**Discussion**

The authors were disappointed to learn that about one third of the cancer center patients were unaware of support groups. Signs are posted in clinic areas, meetings are advertised in local newspapers, and treatment team members strive to encourage patients to attend meetings. It appears that ongoing, intensive, and innovative methods are needed to educate patients about the availability of support groups.

This study has shown that there is an association between gender and support group behavior. Although approximately two thirds of both prostate and breast cancer patients were aware of available groups, women attend at least the initial support group markedly more often than men. Thirty-three percent of the women, compared to only 13% of men, attended at least one support group meeting. This difference could be at least partly accounted for by the fact that the members of at least one national organization, the American Cancer Society-sponsored Reach to Recovery program, attempt to visit women in the hospital or soon after surgery to make them aware of support groups. That visit may serve to recruit breast cancer patients by demonstrating the value of patient-to-patient contact.

One might question whether the gender differences could be attributed to other factors such as the scheduling of meetings. Breast cancer patients were able to choose between monthly meetings held on Saturdays (to accommodate working women) or weekly meetings held during the day on weekdays. In contrast, support groups for prostate patients are held monthly on weekday afternoons and are less accessible for men who are in the workforce. It was initially thought that older age might explain the gender differences because the prostate cancer patients were older than the breast cancer patients (average ages, respectively, 69 years and 60 years). However, the comparison of average ages of attenders and nonattenders for each gender did not support this hypothesis. Breast cancer attenders were younger than nonattenders, but prostate cancer attenders were equal in age to the nonattenders.

The data from the study reported in this paper also reflect that women and men who do attend support groups continue in the group over the same period of time, about 1 year.

Overall, the findings suggest that innovative approaches are needed to reach larger numbers of both patient groups. These data indicate that men who do attend meetings, attend an average of 11 meetings. Clearly, the challenge is in getting men to attend their first meeting. Also important is the fact that a majority of women diagnosed with breast cancer, more than 60%, are not joining support groups. The reasons for this nonparticipation are unknown. There is the possibility that patients with breast cancer are underusing this psychosocial intervention.

In planning this study, an unstated hypothesis might have been that women would come for emotional support and togetherness, and that men would come, if at all, for information. This is based on the premise that men were unlikely to look to other cancer patients for emotional sup-

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**Table 2.** *Comparison by Gender of Reasons for Attending Support Groups*  

<table>
<thead>
<tr>
<th>Reason</th>
<th>No. of Subjects Stating Reason Was Not Important or Somewhat Important</th>
<th>No. of Subjects Stating Reason Was Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learn more about the disease</td>
<td>17</td>
<td>27</td>
</tr>
<tr>
<td>Breast cancer patients</td>
<td>17</td>
<td>27</td>
</tr>
<tr>
<td>Prostate cancer patients</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>(chi-square = 3.20; ( P = .07 ), not significant)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compare situation with other patients</td>
<td>18</td>
<td>26</td>
</tr>
<tr>
<td>Breast cancer patients</td>
<td>18</td>
<td>26</td>
</tr>
<tr>
<td>Prostate cancer patients</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>(chi-square = .74; ( P = .39 ), not significant)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Share concerns</td>
<td>15</td>
<td>29</td>
</tr>
<tr>
<td>Breast cancer patients</td>
<td>15</td>
<td>29</td>
</tr>
<tr>
<td>Prostate cancer patients</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>(chi-square = .99; ( P = .32 ), not significant)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Sample of 44 breast and 19 prostate patients, total \( N = 63 \).*
port. Some support, albeit weak, was lent to this unspoken hypothesis. Men with prostate cancer do state that learning about their disease is “very important” somewhat more often than do women with breast cancer. But interestingly, men report no less interest than women in “sharing their concerns” and “comparing their emotional and physical progress” with other patients. This seems to indicate that if support groups are targeted to men and women, who otherwise might not attend, in a way that “gets them in the door,” the support aspect that comes from being with other cancer patients will be valued by all attendees.

Without diminishing the purpose of the group, a support group could be marketed very differently, first, by calling the group something other than a “support group,” perhaps something like a “men’s information group.” For example, the Suramin Club mentioned in the Feldman study is of an informative nature. This club was organized around information and social activities. Planning a boat ride, attending a football game, or other activity may encourage the nonattender to walk through the door the first time.

An important limitation of this study was the small number of men who attended support groups. Because only a small percentage of men attended, it may be difficult to draw valid conclusions comparing men and women in their attendance behavior. A second limitation of the current report is that reasons for not attending support groups or for attending but dropping out are not offered. Open-ended questions on these and related topics were posed, but an in-depth analysis of these data has not been completed. Preliminary analysis shows that the most common reason for not attending was that the respondent did not feel a need for support, pointing to a good natural support system or to the perception that he or she was not seriously ill. Some respondents indicated actual or potential discomfort in being with and listening to other patients with poorer prognoses. These appear to be valid reasons for developing interventions other than support groups for these patients.

Clinical Implications

All members of the multidisciplinary team play potentially critical roles in encouraging support group attendance. The following specific suggestions are offered. 1) The nature of support groups may need clarification for many patients who believe that these meetings are geared toward emotional support of the terminally ill. It should be emphasized that the groups provide information for persons at various stages of diagnosis, treatment, and illness severity. 2) Ongoing reminders about the existence of support groups are needed. Patients may be highly anxious during initial contacts and will not remember everything they are told, particularly about ancillary and support services. 3) Each team member can encourage and educate patients about the value of support groups. Physicians as leaders of the treatment team can be particularly influential. At the same time, staff members who make appointments may hand out meeting announcements or ask patients whether they wish to be put on a mailing list.

Support groups are underused by cancer patients. Increased efforts to educate patients regarding the availability and benefits of support groups are needed. However, these groups are not a panacea. More research is needed to tailor support groups to different patient populations and to compare their benefits with other methods of addressing the emotional and psychological concerns of cancer patients. Innovative models, such as telephone support groups or computer-based support networks, need to be tried and systematically evaluated.

References