Research Translation:

*Edited by Dr. Florence S. Schwartz. This article is an excellent example of the rapidly expanding segment of volunteerism encompassing self-help groups.*

# A Self Help Group In Action

By: *Norma G. Feinberg, Ph.D.*

Recently, several books have been published relating the individual reaction of writers and medical reporters to their own surgery for cancer of the breast. These books have been informative and have provided valuable research reports to the general public. But what of the woman who is not a medical reporter or a writer? How does she cope with her situation?

At Magee-Women's Hospital, Pittsburgh, Pennsylvania, it was believed by social service and medical personnel alike that this was a crucial time for women and that their needs oftentimes exceed the professionals' capabilities to offer service during hospitalization and post-hospitalization. It was felt that at this time in the adjustment process, dialogue with other women having similar experiences would be of great help. A woman first of all learns that she is not alone, she can learn from others' attempts at resolving their problems and she can benefit from the satisfaction that comes from being able to help someone else.

It was also believed that these women, supported by each other, would be able to increase the understanding of the leaders as to what the problems were that a mastectomized woman encountered, as well as the mutual aid phenomena of common concerns operating in their behalf.

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Initial planning efforts for the group focused on developing objectives for the overall group process. The first step was to formulate the goals of the group. They were delineated as follows:

1. *To provide guidance, support and information needed to adjust to their difficulties which include accepting the changes in their bodies;*
2. *To learn from others' attempts at resolving their problems and ways to deal with and accept their own; and,*
3. *To gain the satisfaction and benefit that comes from being able to help someone else - offering help so as to receive it in a reciprocal fashion.*

The aims of the group approach reflected the belief that the patient's integration into the group was central to a successful outcome.

Letters (N=25) were sent out to women who had mastectomies at the Magee-Womens' Hospital who had no evidence of metastic disease following their surgery. All of these women were patients of the two cancer specialists at Magee-Women's Hospital.

The danger of encountering recurrence for this initial group was possible, it was realized by the group leaders, because of the long time span since the surgery. It was felt necessary to include these women, but, hereafter, new groups would only include recently mastectomized women. New mastectomies were included for the first few months, and some of the original members dropped out. The group then stabilized into a cohesive unit with eleven women meeting at the hospital every three weeks for a period of eight months.

By being a participant observer in the group, the researcher had the opportunity to share in the give-and-take and the positive and negative interactions with the group members. Observations of group process and tape recordings of selected sessions were used to gather data on various categories of positive reinforcement one member gave and received from other group members.

These data seemed to indicate that the group setting provided a therapeutic milieu in which women had the opportunity to compare experiences and express some of their fears and concerns. However, as was found from the responses from the questionnaire administered after seven months of meeting, a few of the women were not sure that the group was helpful to them and one felt that to her, it was anxiety provoking.

One may speculate, of course, about what a woman feels as she passes through phases of her career as a cancer patient. As a result of listening to these women express their feelings, the observer was able to hear certain specific themes consistently expressed. *The four major themes consisted of: 1) the woman's concern about her physical appearance and reaction of significant others to her; 2) interest in the disease and its treatment; 3) disappointment of their physician's lack of sensitivity, lack of time and their unwillingness to keep them fully informed; and 4) fear of recurrence.* These common experiences and feelings about themselves set the stage for mutual comfort and support.

The women were keenly aware of their physical appearance and many meetings were spent in discussing prostheses and the difficulties they posed. From the remarks that were being made and from the questions the women asked, it was evident that the cosmetic aspect of the surgery is not always well-handled and often not considered by professionals. Prostheses are an embarrassing subject, and the group discussed the insensitivity of the market place and the lack of training and support in this area. One member described her first shopping experience as somewhat less traumatic since she was fortunate enough to find a specialty shop with an experienced fitter who was understanding and helpful. The women were grateful for this information. Giving advice and seeking similarities were characteristic of the group in the initial stages of its development.

A beginning goal of the leaders was to help the woman feel that she was not alone in her struggles and to provide the reassurance, emotional support and the opportunity to share feelings and experiences with others "in the same boat". It was not intended to be as educative or informative as it turned out to be, but this proved to be an equally important need that was not recognized initially by the group leaders.

The women repeatedly indicated a desire for specific information about follow-up care. No one had given them this and, under the circumstances, they pressed the professionals for answers. The women themselves were the source of much of the information.

Breast reconstruction was a topic that appeared to interest the group. Most of the women were cognizant of the high cost of this surgery and that most major insurance companies still refuse to pay for such "vanity" operations. Only one group member had been prepared by her surgeon for this surgery. She was concerned that she would be denying her family by indulging herself. Other members disclosed fears of recurrence related to breast reconstruction. The women discussed their signs and symptoms, and as the meetings progressed, they began to search for guidelines in learning to adjust to their surgery. They sought advice from each other as well as from the professional group facilitators.

Although many of the meetings became educative-informative ones, and this seemed to meet the needs of the group at this time as indicated by their responses to the questionnaire, this was not the most helpful factor. *Rather, the members thought that being in close contact with other women who share common problems was most important.*

The group was asked to rank the ten most important items that they felt were most helpful to them. It is significant to add that the same items that were chosen first by many were the second, third, and etc. by the others. It was as if they were saying, "I joined the group to have close contact with other women who share my problems. I found that I am not alone in my struggle, but in the end I must take the ultimate responsibility for my adjustment no matter how much guidance and support I receive from others."

The support the members had for each other elicited their desire to do something collectively to improve upon a health system that gave scant attention to post-operative care. The women who were having complications solicited advice from other group members and pressed their physicians for more specific answers to their questions. One member gave recognition to the group for helping her to take the initial step in insisting on a bone scan to assist in diagnosing her symptoms. This experiment alerted other group members to demand more comprehensive and complete follow-up examinations, especially after the group was informed of her recurrence of cancer.

Conclusions

The most encouraging aspect of the study was that these women seem to be coping admirably with this fearful problem and were able to offer sustenance and support to each other. Discussions with other mastectomees seemed to provide the women with an opportunity to comprehend the trauma they have experienced and better deal with it in a supportive group setting.

The group's development initially went through a stage of orientation, with great dependency on the leaders, whose first task was to promote a feeling of security and a sense of purpose. The leaders explained that the group belonged to the members, and they were to determine the topics for discussion. As the group progressed, the co-leaders served as resource people, but if the meeting was slow in starting, they made suggestions, in the form of observations, to get the group session started.

After the initial reviewing and sorting of their experiences, the women were able to move to an examination of their current feelings. Some who had passed the initial adjustment provided reassurance and understanding to those who were presently facing it. This developed into a trusting relationship where it was possible to verbalize their natural feelings and to specify some of their most pressing concerns.

Moreover, the strong marital and family relationships, plus other personal attributes in members, appeared to be a moderating force which helped promote successful adaptation for this group. Nevertheless, there was convincing evidence that physical discomfort, lack of medical attention, and fear of recurrence caused them considerable stress. This suggests that the impact of this experience was more than it might appear on the surface. The use of the group process permitted them to verbalize and use the combined strengths of the group to overcome weaknesses in coping with the psychosocial components of mastectomy.

It must be remembered that the women were at different stages of adjustment. All women who had surgery for breast cancer within a two-year period of time, without metastases, were invited to join the group. Even though it was reassuring for new mastectomees to meet with others at varying stages of improvement, it may have been less reassuring to identify with those who had a recurrence of cancer during the eight months' time period of group meetings.

It is suggested that future group planners consider these factors, as well as group size, group composition, scheduled meeting times and time limits. This type of pre-planning will avoid some of the problems, especially that of termination, which this group had encountered. If some of the women feel that they would like to be involved further with a group, they should be encouraged to organize their own groups* or be asked (after screening) to join new groups of recently mastectomized women to offer their insights and to demonstrate what they have learned from their group. In this way, they will not only be helping others but will be adding to their own strengths in sharing their experiences.

*The members were asked on the questionnaire if they were willing to organize similar groups of women and six responded "yes".

*Finally, as in this group, the leaders should have the ability to develop rapport, and have the capacity for warmth and interest in others. They will have to be prepared to deal with the major needs of these women, including understanding the medical aspects of cancer with its corresponding psychological issues, even though it is not clear if the knowledge gained is productive or anxiety producing for its members.*

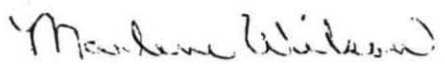
# *Letter from the Editor*

With this issue, I complete my term as Editor-in-Chief of Volunteer Administration. I am gratified to be leaving it in the capable hands of Chris Dolen. I wish her every success.

It is inevitable that nostalgia becomes a part of leave taking - so I will indulge in it for a moment. Two and a half years ago, we set as our goals: 1) to establish a sound fiscal base and reliable publishing schedule for the Journal; 2) to substantially increase the readership; and 3) to enhance the Journal's value to the field by increasing the number of articles written by and for practitioners and volunteers. I am delighted to say we have achieved a measure of success in all three areas. It has at least begun to make a significant movement toward becoming the respected professional journal it deserves to be.

Many people have made sizeable volunteer contributions of time, energy and expertise to help this come about. The two Managing Editors who served with me, Carol Moore and Hilda Palm, deserve special recognition for their outstanding work. The support and effort of the Editors and reviewers of all three sponsoring Associations have been invaluable. And finally, you - the readers and authors, have risen to the challenge. I am indeed grateful to you all.

This has been a significant growth experience for me personally. I feel so fortunate to be in a field where we are all "learners on the way to becoming". I eagerly await the frontiers yet to be explored in the upcoming issues of the Journal.



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