Structured cancer support groups: A valuable piece of the cancer care mosaic

By Sandra Freedhoff

Abstract
Individuals with cancer and their caregivers may be taught a variety of strategies to cope with the stresses associated with the uncertainties of the diagnosis and treatment of cancer. This article describes a cancer education and support program to teach these strategies. Program facilitators enhance the sharing of ideas and problem solving among participants, provide resource information, and establish a "caring, warm and safe" environment. The success of the group was reported by the participants in that they reached a new plateau in coping with problems related to their cancer and other areas of life, practiced relaxation to reduce their stress, and had a feeling that they were not alone in their struggle. Structured support groups make a valuable contribution to the mosaic of cancer care.

Introduction
Facing cancer and its treatments is a stressful time. Those persons touched by cancer have increased emotional anguish and will use a number of strategies to improve their ability to cope. While some depend on family support and some manage on their own, others seem to benefit from group interaction. A number of years ago, I chose to become involved in offering a cancer support group for patients, their family and/or friends. This program focuses on an educational component and encourages patients and caregivers to learn to assert themselves, to become empowered, and to ventilate and express their feelings. People who learn and use these strategies have demonstrated more effective problem solving in resolving difficulties experienced and more effective coping. Patients have shared with health professionals the need for acquiring skills to help them manage stress and to communicate better re: issues with family, friends and the medical profession subsequent to the diagnosis of cancer. Finally, people need a network of others going through the same experience. Studies have shown that self-help groups provide a cost-effective complement to professional health care services (Ontario Medical Review, 1991).

The purpose of this article is to describe the experiences of facilitating a structured cancer group - Living With Cancer II (LWC II). The program was initiated under the auspices of the Canadian Cancer Society, Metropolitan Toronto District. The material described comes from six years of experience in forming and facilitating this program. It is anticipated that sharing this information will help others who may want to form similar groups.

Background
Traditionally, nurses, have not been highly involved in offering group support programs. Currently, group programs may be led by a variety of health professionals such as psychiatrists, social workers, nurses, psychologists, or occupational therapists. In addition, increasing numbers of groups are led by lay volunteers who themselves have had cancer.

Groups may have various goals including education, therapy and self-help. They may be structured on the basis of different models for participants and facilitators. Papell and Rothman (1980) described three models: a) the traditional social goals model which emphasizes developing member participation and preventing social problems, with the facilitator in an enabler role; b) the remedial model which seeks individual change, with the facilitator taking a central role in planning and leading the group as well as assuming a major therapeutic role and c) the reciprocal model, developed by Schwartz, which focuses on personal social change through the mobilization of a mutual helping process between peers facilitated by the leader. The LWC II groups are structured along the reciprocal design.

Many well-known social workers have done much work in the field of support groups: Tropp, Schwartz, Goroff, Alissi, and Lindeman (Alissi, 1986). As well, there have been many studies completed in the area of group support for counseling cancer patients, including David Spiegel et al (1978, 1979, 1981), Irvin Yalom (1981), Mary Perle (1979), Christian and Michael Teich (1980), Karrin Ringler (1981), and Mary Vaillancourt (1986).

A landmark study by David Spiegel was commenced in 1981 and the results were published in 1989. Eighty-six women with metastatic breast cancer were randomly assigned to a control group or a supportive therapy group. The therapy group met weekly for one year for psychological support plus training in self-hypnosis for pain control. Both groups received standard medical treatment. Patients in the therapy group lived an average of 18 months longer than those in the control group (p<0.0001) (Spiegel, Bloom, Krameser & Gottheil, 1989, p. 890). Three reasons have been suggested by Spiegel as to why the therapy group did better - 1) the support in some way enhanced the effectiveness of the medical treatment 2) the support may have lessened...

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ABRÉGÉ

Il est possible d ’ enseigner, aux personnes souffrant du cancer et aux prestataires de soins, diverses stratégies permettant de faire face au stress qui accompagne les incertitudes du diagnostic et du traitement du cancer. Le présent article décrit un programme d ’ éducation et de soutien qui permet d ’ enseigner ces stratégies en question. Les animateurs du programme facilitent les échanges d ’ idées et les résolutions de problèmes au niveau des participants, fournissent l ’ information en matière de ressources et établissent un environnement " affectueux, chaleureux et sûr " . Les participants ont indiqué que les groupes réussissaient parce qu ’ ils leur permettaient d ’ attendre de nouveaux pousses en ce qui a trait à leur façon de faire face aux problèmes qui accompagnent le cancer et à d ’ autres aspects de leur vie. Les participants s ’ adonnent aussi à la relaxation afin de réduire leur stress et ils sentaient qu ’ ils n ’ étaient plus seuls dans leur lutte contre la maladie. Les groupes de soutien structurés contribuent largement à la mosaïque des soins du cancer.

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depression improving patients' appetites, leading to better nutrition and 3) controlling pain through self-hypnosis allowed patients to maintain a greater degree of normal activity. Although this is only one study, it certainly opens the door to think about support group approaches. (Spiegel, Bloom, Kraemer & Gottheil, 1989, p. 891).

The connection between mental processes and illness is being vigorously evaluated by an emerging discipline called psychoneuroimmunology (PNI). This discipline explores the connection of the endocrine system, the nervous system, and the immune system - or the mind/body/spirit connection. It is hoped that more research will be done on the body's response to disease through attitude, spirit and faith. PNI studies how psychological interventions affect the immune system. There is a possibility that psychological support increases the activity of natural killer (NK) cells in the body which specifically target virus and tumour cells. Researchers consider the NK cell to be the body's first-line immune system defense which appears to be sensitive to emotional states. A number of studies have found that depression can inhibit the activity of these cells. (Johns Hopkins Medical Letter, 1990).

The benefits of group work as opposed to individual approaches have been reported by various authors. Several types of benefits have been described. One example is the theory of universality - or "all in the same boat." Proposers of this view argue that it helps to decrease the feelings of being singled out and of isolation (Spiegel & Yalom, 1978). Others address the role of the experience of altruism. In a group, such giving emerges through the act of helping oneself by listening, observing and helping others. The following therapeutic mechanisms have been suggested to account for the effects of supportive group therapy: Catharsis, a "sense of community with others experiencing the same situation, and feelings of altruism and worth that accompany giving and receiving support" (Telch & Telch, 1985, p. 330). Learning alternative coping skills can result when group members act as role models for each other. Group interaction can often increase a member's self-worth, value, sense of control, and usefulness. A feeling of group cohesiveness can occur when individuals feel their common needs can be satisfied by belonging to the group (Zander, 1983).

Living With Cancer II group development

Approximately six years ago, I decided I wanted to take the orientation course to become a group leader for the Canadian Cancer Society - LWC groups. At that time there were probably about two to three such drop-in groups in Toronto and they were poorly attended. I felt I wanted to volunteer in a structured program. I had just become a member of the LWC Advisory Board of the Canadian Cancer Society. With my encouragement, this board of health professionals developed the program described in this article, based on their clinical experiences with cancer patients.

Program structure

For the purpose of this paper, the definition of a group will be "a dynamic social entity composed of two or more individuals, interacting independently in relation to one or more goals that are valued by its members, so that each member influences and is influenced by every other member, to some degree, through face to face communication." (Bertecher, 1979, p. 14).

The groups in LWC II consist of 8-16 cancer patients and/or support persons. The goals for the program are: 1) to increase their understanding of the cancer disease process through speakers on such topics as nutrition, relaxation, relationships and communication, humour, and future directions. 2) To share their feelings and experiences through verbalization, listening and responding. 3) To promote the use of positive coping skills to manage stress associated with the diagnosis and treatment of cancer thus improving their quality of life, and 4) to decrease their sense of isolation.

Participants (cancer patients, their family and/or friends) generally hear about the groups by word of mouth, by phoning the Canadian Cancer Society, and/or through pamphlets distributed to various locations such as out-patient clinics, doctors' offices, etc. Group members must register beforehand in order that we can manage the size of the group and get some kind of commitment from the members for their participation. Usually two groups are held each year - spring and fall, the reasons being that weather and vacation time all have a bearing on attendance.

The LWC program was developed as a six-week session of two-hour weekly meetings. This program helps individuals to learn from others about personal growth and sharing during a traumatic experience. Individuals are empowered to make appropriate choices in their own care and decisions in their own life. They are made aware of available support services in the community and are shown how to utilize them. Nutritional information is discussed and specific issues are resolved. A focus on improving relationships with family and friends through better communication skills is a vital part of improving one's coping skills. Members learn to utilize stress management techniques such as relaxation, imagery, visualization and meditation. These are just some of the strategies used to increase an individual's coping skills when faced with a life-threatening experience.

Each meeting includes a presentation and discussion on a particular topic (See Table One for specific details). The topics include nutrition, relaxation, relationships and communication, humour, and future plans and goals. Flexibility is of vital importance in this program. For example, the first time we offered the program, the fifth evening was on the topic "the importance of children." The participants told us, after the first session, even though the speaker was excellent, the evening ended with a negative feeling instead of members feeling uplifted and more positive. This was not the goal for the support group. The topic was changed after the first program to "smelling the roses" which includes humour and a focus on improved quality of life. This order of topics is maintained unless feedback from the group members indicate a need to change.

Table One: Structure of Living With Cancer II sessions

<table>
<thead>
<tr>
<th>Each evening has a presentation and a discussion period. A break for 15 minutes occurs halfway through the evening. Each evening ends with an evaluation and relaxation exercise.</th>
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<tbody>
<tr>
<td><strong>EVENINGS</strong></td>
</tr>
<tr>
<td>1. Introduction to Canadian Cancer Society and its resources. Members are welcomed, introduce themselves by talking about their cancer, treatment, family and hobbies. Book list is reviewed and lending library is explained.</td>
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<tr>
<td>2. Open discussion: Pertinent issues from week before and update on any personal events within the group. Reducing stress through relaxation techniques - speaker describing actual theory of stress and stress reduction using relaxation and imagery techniques.</td>
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<tr>
<td>3. Open discussion: Issues surrounding relaxation and its application. The power of positive eating - speaker covering such topics as: Canada's Food Rules; high fibre; low fat diet; alternatives to certain foods; macrobiotics.</td>
</tr>
<tr>
<td>4. Healing your relationships through improving your communication skills - speaker dealing with such issues as: Listening skills, taking one day at a time, learning to express feelings and thoughts to loved ones and friends, review of psychosocial book list.</td>
</tr>
<tr>
<td>5. Smelling the roses - How to develop your humour resources and incorporate complementary therapies in your life along with standard medical treatments. Video is shown on humour which describes the theory and value of laughter to improve quality of life. Review of the complementary therapies available in Toronto such as: Massage, shiatsu, reflexology, relaxation programs, hypnosis, music and art therapy, exercise.</td>
</tr>
<tr>
<td>6. Where do we go from here? - we have a pot-luck or catered dinner. An alumna from a previous session attends and discusses how he/she has dealt with their disease since diagnosis, treatment and survival. Discussion follows regarding any issues important to the group. Closing remarks and networking.</td>
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The groups are led through a facilitation style. Throughout the program there are always two facilitators leading the group. We have two facilitators for several reasons: We can support or back up each other during the evening; we have an opportunity at the end of each evening to discuss any problems from that night and decide on issues that need to be addressed the next evening; and if a facilitator is unable to attend an evening, there is always someone available.

The facilitators are always health professionals - nurses, social workers, occupational therapists or radiation therapists who have a specific interest in leading support groups for those individuals touched by cancer. There are two-day workshops for training facilitators, sponsored by the Canadian Cancer Society - Ontario Division. The potential facilitators are also given an opportunity to be an observer in a group already functioning. They state that they feel much more confident leading a group after having had the training and observing a group.

The facilitators’ responsibilities are to organize the group meetings in terms of setting, time and structure. However, the critical responsibility for a facilitator is to encourage group members to participate by seeking to help each other. Therefore, it is important for the group members to learn from each other and not depend on the leader for answers. Norman Garoff states "that the basic power to help people in a group resides in the people in the group" (Alissi, 1980, p.298), and I believe that to be true.

**Challenges in group work**

There are a number of challenges in working with groups. The introductory and closing evenings present challenges. "Beginnings and endings are hard for people to manage - they often call out deep feelings in both workers and members" (Alissi, 1980, p. 278). My experience supports the view that the introductory evenings are difficult for both members and facilitators. It is often the first time that a member has stated openly that he/she has cancer. The group members are all strangers to each other and do not know what to expect, therefore there is a lot of uncertainty. The first meeting sets the stage for the remaining meetings by enabling members to feel comfortable in the group, to begin to trust that the other members will make it a safe place to share feelings, and to look forward to the rest of the meetings in a positive way.

At the first meeting, the issue of confidentiality is discussed to ensure the members understand its tremendous importance.

The closing or ending night is important because it gives members the opportunity to assess what they have gained during the group sessions. Some participants need time to cope with feelings of frustration or sadness about the loss of the networking and support which the ending of the sessions may engender. We encourage members to go on to another group experience if they wish, or to continue their group themselves with the facilitators acting as consultants. Every group has acknowledged a desire to continue meeting, but none have been able to accomplish this on an on-going basis. A few groups have met socially (eg dinner or drinks) or attended a lecture presentation. We encourage the members to think of the time of ending as a time for a powerful beginning towards a new approach to life.

The meetings are considered closed meetings - members cannot just "drop in" whenever they want. Members are required to register beforehand. Before the group commences, I phone each person to introduce myself and find out about their intention of joining. I always encourage patients to bring a support person, either a family member or a friend to the meetings. Only a small number do not want to bring someone or do not have anyone to accompany them.

**Limitations of group work**

Limitations may arise in offering support groups to the community in that some people are afraid to speak about their illness with others for various reasons: They do not want to talk about their affiliation; they feel they are different than others - others will not understand what they are feeling and experiencing; they have had no encouragement from their family, friends, or their physicians that groups might be helpful; and they are better on a one-to-one level.

Another limitation that I have experienced is that of attendance. There is always the chance that even though 20 persons have registered, the number can decrease for many reasons - a patient became ill during the sessions; patient had treatment that day and was unable to attend; another commitment took precedence; and rarely, there is a lack of interest (just not the right path for them).

On an average, approximately 12 persons attend our sessions. It fluctuates every week and every session. When there is a good attendance, the interaction during the evening flows much better. With a fewer number of participants, less sharing takes place, and any quiet, shy members are put under more pressure to participate.

**Strategies used to enhance comfort at each session**

As experience has shown, people are anxious about attending the group, so we begin our modelling strategies at the outset of the meetings. For example, we play relaxing music as the group members enter the meeting room because it helps to set the tone for our time together. To enable networking, name-tags (using first name only) are worn. A volunteer is present at all the meetings along with facilitators to greet the members. The volunteer use is carefully selected for her ability to show interest in individuals by her warm, caring personality and her commitment to be present at all six meetings. Refreshments (either bought or homemade goodies) are served.

We have found the best arrangement is having us all sit in a circle, so that everyone is in view. We believe that any tables in the middle of our circle may inhibit communication. The facilitators sit across from each other so we can maintain good eye contact with each other and members will not feel threatened by our sitting together.

At the first meeting, we ask group members to introduce their disease site, if they received treatment, and some information about themselves as a person. Members are encouraged to talk about hobbies, family and work. This puts everyone more at ease and they are able to find common bonds other than just their disease. In our first evening, we distribute and explain an information kit about the resources of the Canadian Cancer Society. We discuss our lending library and our book lists. Adding an educational content to the meeting is a way of alleviating the members’ anxiety of having to speak the first night. It is stressed that this is their group. It is important for them to have input and receive feedback which will grow as the members get to know one another.

Halfway through each meeting we always take a break so that everyone can get refreshments and socialize for a few minutes. A great deal of networking occurs at this time and the opportunity exists for people to make special “connections” with one another.

We encourage positive and negative feedback from participants to facilitators to enable us to improve on the next group and learn from our mistakes. At each meeting, group members provide written feedback in a simple evaluation form. The evaluation form covers such areas as: Whether content of topic was clear and easy to understand, if the participant was able to ask questions in comfort and with enough time, if the group made members feel safe and supported, if facilitators were effective, and if the session helped members cope better. We believe it is especially important for members to offer feedback in the areas of feelings, relationships and goals being accomplished. We can make changes in the meeting format if the members indicate it would be more helpful. Our form has a place for suggestions for improvement. The forms are either completed at the end of each meeting or filled out at home and returned at the next meeting.

Each evening always ends with some form of relaxation technique - using either active or passive relaxation, imagery, or visualization which is usually done to appropriate music. A variety of techniques are used to give members the opportunity to discover the ones they are most comfortable with and might use in the future. Relaxation is our first topic so that our members can understand early the benefits derived from practising this technique.

All the speakers we use are professionals from different areas of Toronto - highly qualified and suitable for the group. If people in the group also have expertise we can utilize, we ask for their participation. Our groups have used the expertise of a play therapist, a nurse, a chaplain, and an individual knowledgeable in a specific relaxation technique he had learned elsewhere.
Throughout the six-week session, handouts are given to members pertaining to the topic of the evening. Also, we have posted on a corkboard any items (eg articles, newspaper clippings) related to the evening’s topic. Appropriate cartoons are frequently used. Every week a different quote is written on a flip chart to give the group food for thought. The intention of these meetings is to keep the evening on a light vein with some humour, but still be able to handle the serious issues. In the discussion, we attempt to focus the attention on issues, not the type of cancer. It has worked out very well and very little of the discussions have turned to site specific issues.

A good facilitator contributes to the success of this group. Trapp talks about the humanistic theory where the facilitator is placed in a common human perspective within the group (Alissi, 1980). "Each facilitator brings his own personal style, artistry, background, feelings, values, beliefs, and so on, to our professional practice" (Shulman, 1984, p. 13).

The facilitator must be knowledgeable of and skilled in counselling and group dynamics. If there is negative feedback such as anger, boredom, long silences or dominating members, an uncomfortable situation may arise. Every group facilitator ought to be comfortable with skills such as the following: 1) attending - watching and letting the group know you are paying close attention to what is being said and done; 2) seeking and giving information; 3) controlling negotiations; 4) rewarding and reinforcing through feedback positive behaviour towards goals of group; 5) responding to feelings with empathic ability; "genuine empathy involves stepping into the client's shoes and summoning an effective response which comes as close as possible to the experience of the other" (Shulman, 1984, p. 67); 6) focusing on an issue to increase participation; 7) summarizing responses in one statement for clarity; 8) gatekeeping to encourage equal distribution of participation; 9) confronting individuals in a constructive, friendly manner to change their behaviour; 10) modelling by either member or facilitator in actions or words; 11) mediating between members to avoid or resolve a disagreement that is keeping the group from reaching its goals; and 12) starting or beginning a group meeting or introducing a new topic (Betteche, 1979). The facilitator ought to see each member in the group as an individual but be able to also observe the group as a whole.

In addition to the two facilitators and the volunteer, each group has an observer who is either a social worker, chaplain, nurse or potential group facilitator. This is encouraged to allow others to benefit from observing a successful group process. The observers' input at the end of each meeting is very beneficial. It is important for us to finish on time, in order that there is an opportunity for the facilitators, volunteer, and observer to meet to review the evaluation forms and to discuss any problems we encountered during the evening. This gives us a platform to prepare for our next meeting.

Groups available in Toronto

At present, in Toronto, there are a number of choices of group programs being offered to people touched by cancer. There are specific groups available in hospital at the time of treatment, out-patients centres offer drop-in groups also for those receiving treatment, there is a seven-week course organized by Dr. Alastair Cunningham - Cancer Coping Skills Training Program at the Ontario Cancer Institute. Wellspring, a community based centre for people with cancer, offers a five-week support group for patients and family members. Last year, the Canadian Cancer Society offers drop-in groups in various areas of the province (five in Toronto) and the structured, six-week course I am describing in this paper. "Group interventions either by professionals or in self-help groups may be helpful for some people, but they are not necessarily a panacea - nor an appropriate form of intervention for all people with cancer" (Vachon, 1986, p. 213). Therefore, I always mention to patients that groups are not for everyone, and not to feel badly if they are uncomfortable or nervous about entering a group. Often one-to-one support or help may be the answer.

What I have personally learned

Facilitating groups has been a tremendous learning experience for me. From my experience I have learned the initial phone call to new people wanting to join the group is invaluable. The personal touch and interest encourages them to want to attend and have some kind of commitment. I have also learned the size of the group is of vital importance - the more members, the better the sharing. There is more interaction and it gives the shy, quiet members a chance to just listen without feeling pressured to speak. Flexibility in approaches must be applied to every group, since every group is unique. Although each group is different and presents its own set of challenges, the fundamental approach remains consistent. Over the years I have felt a personal growth in such areas as self-confidence, self-worth and capability. I have had a wonderful opportunity to work with very proficient, knowledgeable facilitators who have taught me so much. Not only have my listening skills improved, but also my speaking skills. My ability to express myself more clearly, and my counselling skills have improved with each group. I have been made aware of the importance of living and enjoying each day, of smelling the roses, seeing the sunsets, and feeling for everyone in a sensitive, mature, empathic manner.

Future considerations

It is obvious from the feedback of the group members, their satisfaction and benefits derived from the group. A feeling of intimacy occurs among the members which is very special. There is an exchange of phone numbers and good wishes. They reported that they are not the same person who started six weeks earlier. Members in the group stated they were less fearful of the misconceptions associated with the diagnosis of cancer, and were more willing to ask questions about their cancer and its treatment. They said they had a better knowledge of the agencies and resources available in the community and felt confident in accessing these agencies. They expressed more comfort in talking with one another in the group as well as with their family members, friends, and other health professionals. "Intervention approaches differ in the strategies used but share the common goal of minimizing patients' distress and improving quality of life by enhancing patients' coping" (Teleg & Teleg, 1985, p. 330).

The Needs of Ontario Cancer Patients Project was completed in May, 1990, by the Ontario Division of the Canadian Cancer Society (Abbey-Livingston, 1990). The report reflects patients and families have unmet emotional needs and are asking for help in dealing with
these aspects of cancer. There is also a suggestion that help in dealing with the emotional aspects of cancer can best come through people who have had personal experiences with cancer or possess a strong interest in helping people with cancer. One of the recommendations was to strengthen the development and delivery across the province of peer support services. Group experiences such as those described in this paper are an example of peer support services.

Summary
This paper describes the experiences of facilitating a structured group for cancer patients and their support persons. The organization and format for the group was outlined as well as the critical elements for its success. A timeline for organizing support groups is presented (Table Two). It describes the time plan used to complete the tasks necessary to organize the sessions as efficiently as possible. Group members reported positive gains from their experiences with the group. It is anticipated the information described here will be helpful for those interested in starting a group or wanting to apply these ideas in the work setting.

In conclusion, it is vital for the future of support groups that more recognition be given by health professionals, including physicians, to encourage patients’ participation in such an activity. It is our responsibility to educate those who are not aware of the value and importance of patients’ needs for not only physical but also emotional support.

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References