Cancer Support Groups

A Guide for Facilitators

American
Cancer
Society®

Cancer Support Groups

A Guide for Facilitators

Joan Hermann, MSW, LSW
Fox Chase Cancer Center

With a special chapter on telephone and online support groups by Yvette Colón, MSW, ACSW, Cancer Care, Inc.

American Cancer Society®

ISBN: 0-944235-35-2

Printed in the United States of America

Group membership, acceptance, and approval are of the utmost importance — I have seen a group mourn the death of one of its members and another group physically carry one of its members to the hospital. Relationships are often cemented by moving or hazardous adventures. How many relationships in life are so richly layered?

— Irvin D. Yalom,
The Theory and Practice of
Group Psychotherapy

Contents

Acknowledgments

This book is the third in a series of American Cancer Society publications devoted to support group interventions. It is dedicated to the community of people, lay and professional, who are involved with and care about people whose lives have been touched by cancer. There have been two previous editions, one titled *Guidelines on Self-Help and Mutual Support Groups,* published in 1988, and the most recent, *Guidelines on Support and Self-Help Groups,* published in 1994. This book draws heavily from these previous editions, and we gratefully acknowledge the many people who contributed to them. These include, for the 1988 book, Catherine Cordoba, Maxine Bernard Shear, Pat Fobair, and Joan Hall; for the 1994 book, Marie M. Lauria, Wayne Dorris, Nancy Wells, Susan C. Hedlund, Diane Morrison, Doretta Stark, Naomi M. Stearns, Susan M. Stensland, Virginia Vaitones, Glenda Kelman, David Cella, Berton H. Kaplan, Barbara Berkman, Frederick Cohen, Jerome Cohen, Helen Felsenthal, Gerald Goldstein, Robert J. McKenna, Sr., David K. Wellisch, William Worden, Holly Danforth Vugia, Margaret A. Pierce, and Arlene Robinovitch.

Professional social workers, psychologists, and nurses have traditionally been the principal facilitators of oncology support groups. However, cancer survivors and the people who care about them have also organized and facilitated groups. Both lay and professional facilitators have shared their insights with us and enriched our practice, thereby enhancing the content of this book. We are grateful to them for their dedicated service.

Special thanks are due the following members of the Social Work Oncology Network, the listserver of the Association of Oncology Social Work, who contributed their insights about support group facilitation: Lynn Behar, Kim Criswell, Marcia De Sonier, Susan Everly, Matt Loscalzo, Kathy Meyer, Lisa Parsonnet, John Sharp, and Les Gallo Silver. I am also grateful to Jerry Carter, Arlene Robinovitch, Marie Lauria and Noni Stearns for their clinical wisdom and support; and to Diane Blum of Cancer Care and Carol Marcusen of USC/Norris Comprehensive Cancer Center for their help with the Resources section.

American Cancer Society staff who inspired this project are Greta Greer and Claudia Bannon, both of whom have devoted themselves to the development of psychosocial services as an essential component of quality cancer care. I would also like to thank Rosemarie Perrin, consulting project manager, for her expertise, thoroughness, and attention to detail in bringing this edition to completion; Pat Mabley, who provided valuable editorial services and advice; and the Society's production staff, Tom Deal for production of the book, Janet Weaver for design, and Bev Greene and Harriet Zoller for proofreading support.

Joan Hermann, MSW, LSW
Philadelphia, Pennsylvania

I would like to thank Beth Friedman, CSW, Stephanie Stern, CSW, and Amanda L. Sutton, CSW, at Cancer Care, Inc., for their pioneering work in facilitating online groups and developing online group theory.

Yvette Colón, MSW, ACSW
New York, New York

Introduction

People with cancer are living longer than ever before. In many cases, they are being cured of a disease that once was considered catastrophic. Today cancer is more often perceived as a chronic illness rather than one that is inevitably terminal. You will hear people talking about cancer “survivors” instead of cancer “victims.” Survivorship means different things to different people, but regardless of its meaning to a particular individual, people with cancer are interested in living with cancer, not dying from it. This means they can continue to participate in daily activities with the goal of achieving the highest quality of life possible.

Helping people survive cancer is not enough if the quality of their lives has been seriously compromised. Support-group services are one source of help for people dealing with the emotional and family problems that can result from chronic illness. Recent research[1, 2] underscores the positive effect of group participation on an individual’s ability to cope and on a person’s own evaluation of his or her quality of life. Some cancer treatment centers are fully staffed with professionals who are trained to help people cope psychologically with their illness; others struggle just to meet their patients’ basic medical needs. Even those institutions that are hard pressed to provide support services in the current climate of managed care and reimbursement constraints have an ethical responsibility to do so. Saving a life that has been deprived of its spirit is not a successful outcome.

> ***Survivorship means different things to different people, but regardless of its meaning to a particular individual, people with cancer are interested in living with cancer, not dying from it.***

This book provides guidelines for organizing and maintaining support and self-help groups for individuals and their families who are struggling to regain wellness after an experience with cancer. Support groups offer a tremendous source of information and can give people hope for the future. They also offer the strength that comes from the power of human relationships and the ability of people to nurture and support one another. Support and self-help groups can be facilitated by cancer care professionals or by persons with cancer who have completed active treatment.

For People with Cancer and Their Families

Most people with cancer remember the time of their initial diagnosis as one of fear and uncertainty. Their lives were suddenly turned inside out as they struggled to understand the world of cancer treatment, how to enter that world, and how to emerge from it as a whole person. Nothing is the same after this experience; the predictability of life is shattered, and people wonder where they will get the strength to endure. Despite the reality of statistics supporting improved survival rates, most people with cancer initially are frightened and worried about dying, medical treatment, and their ability to meet their responsibilities at home and at work. These concerns can lead to feelings of isolation at a time when the person with cancer most needs other people. Finding someone with whom to talk and share experiences can ease the sense of isolation and reduce stress.

Although hope for the future gradually resumes upon commencement of medical treatment, most people soon realize that the boundaries of dealing with cancer extend beyond medical therapy. People with cancer will often depend on their families and friends to help them meet the challenges ahead. Another significant source of help is other people who are coping with the same problems and issues. People who are dealing with a cancer diagnosis understand each other in a unique way, and that uniqueness can be a tremendous aid to those who take advantage of it. Support groups offer a way to connect with others who truly do understand how cancer can seem to change life forever.

People actively engaged in the cancer experience may wonder how a support group could possibly help them. Those who have never attended one might imagine that support groups are full of people telling sad stories. People certainly do share their fears and worries, but they also share their experiences about successfully managing the uncertainty that cancer brings into their lives. Support groups can be tremendously useful, even inspirational, as one learns from others who have "been there." Those who have experienced cancer have a special wisdom, and that wisdom can be called upon to help bring back some order to life as the challenges of this illness are addressed. Each person confronted with cancer has a history of problem solving, but cancer presents a myriad of feelings and situations that may be quite different from any that have been encountered in the past. Solutions to the problems that cancer presents are available, but individuals need exposure to multiple methods of problem solving in order to regain control, take charge of life, and move on after treatment.

In addition to helping people who are in the throes of a new cancer diagnosis, groups can also help persons whose active treatment has ended. Such help often takes the form of the experienced individual "giving something back" after what often is months of receiving a great deal of attention and support during treatment. This kind of sharing can make people feel good about both the group and themselves.

Participating in a group also gives a cancer survivor a sense of belonging. The group offers members a safe place where their feelings are accepted and understood. It provides a forum for openly talking about fears or emotions they may feel uncomfortable discussing with people outside the group. In addition, group participation provides exposure to several viewpoints and shared experiences, which helps people find a way to manage their own fears as well as those of their friends and family. The American Cancer Society has long been a proponent of self-help and support groups. In November, 1992, their National Board adopted the following policy statement:

> As many well-controlled studies indicate that appropriately designed and supervised support groups improve the quality of life of cancer patients, the American Cancer Society encourages them as a valuable and cost-effective component of comprehensive psychological services in cancer care.

For Cancer Care Professionals

Many cancer treatment centers today offer support groups, but the nature of these groups can be quite different depending on the population served, time and space constraints, urban or rural location, funding sources, and a myriad other factors that influence how people get help. Groups form in hospitals, private homes, community agencies, on the telephone, and even on the Internet.

Oncology social workers and nurses at a hospital or other institution often facilitate support and self-help groups in keeping with the institution's commitment to comprehensive cancer care. These professionals are aware of the issues that confront cancer survivors and their families. Their mission is to help people deal with the physical and emotional consequences of a cancer diagnosis and subsequent treatment and to assist them as they resume their lives after treatment.

Oncology nurses or social workers typically see their roles as supporting people with cancer and their families as they cope with treatment demands, helping them manage their anxiety and uncertainty, and empowering them to continue to function and meet the responsibilities of their lives. People undergoing cancer treatment need not only excellent medical care but trust in the physicians, nurses, and social workers who are caring for them. They require emotional support and information about solving cancer-related problems. While professionals can provide much of the support and ideas for problem solving, it may be more meaningful for people who are actually living with cancer to help one another, because they themselves are the only true experts. The challenge is to harness that expertise in ways that will benefit as many people as possible.

This book provides a blueprint for organizing and delivering group support programs. It is directed primarily toward people who are new to oncology or to group facilitation. It provides guidelines for recruiting members, dealing with difficult behaviors and group dynamics, making appropriate interventions, identifying and working with special populations, and evaluating the group process.

You will note that throughout the text, there is information about problems that arise in facilitating support groups. If you are new to oncology or to support group facilitation, you may not know that support groups can be quite difficult to organize and maintain. You may think that cancer survivors and their families should have no reluctance about joining a support group and that support groups are a universally positive experience. This is usually not the case.

As those experienced in oncology support groups know, putting together a successful group is very labor intensive and often quite frustrating. Survivors and their families may be reluctant to try a support group because of what they imagine goes on. Many prospective group members worry that they will hear sad stories and become depressed when what they need is to feel positive and upbeat about their future. While they certainly may hear about the challenges people are experiencing in controlling their cancer, members can also be inspired by the courage and tenacity of others. Reframing negative thinking is a key function of most support groups, and it is this that people really need in order to enhance their ability to cope with the disease. Patients and their families should be encouraged to try one or two meetings before they decide if a support group will be helpful to them.

Oncology social workers with graduate degrees may have taken course work in support group intervention or had such experience during an internship in a health care setting. The formal education of oncology nurses may or may not have included instruction for facilitating a support group. Even these professionals will be anxious about facilitating a group until they gain experience and become more confident in their skills.

Fortunately, several avenues for acquiring confidence are open. Reading about group facilitation should be a prerequisite to organizing a first group. We have provided references to other material written by people with extensive experience in oncology or group facilitation, in addition to the information in this book. Enrolling in continuing education courses in the community is another option. Professionals in large facilities can identify others who are working with groups and ask to observe some sessions. Co-facilitating with a more experienced person is often the best way to learn and can be a rich experience. Co-facilitation may not be possible, given the constraints of today's health care system. If possible, it is best to team up with someone of another discipline who has more group experience. Oncology social workers and nurses often facilitate groups together; nurses are experts in disease-related issues, and social workers have expertise dealing with emotional issues and coping strategies.

Regardless of the genesis of a group, clinical experience with cancer survivors will teach health care professionals the most about dealing with cancer-related issues and problems. Cancer survivors can teach others about coping, resilience, surviving and even triumphing in spite of adversity. Support groups can help cancer survivors and their families and friends harness the energy necessary to overcome the challenge of cancer. Participating in that journey with people struggling to survive will also greatly enrich the lives of others and help them help others. It is a privilege to share in that journey.

References

1. Taylor SE, Falke RI, Shoptaw SJ, Lichtman RR. Social support, support groups and the cancer patient. *J Consulting Clinical Psych.* 1986;54:608-615.

2. Vugia HD. Support groups in oncology: building hope through the human bond. *J Psychosocial Oncol.* 1991;9:89-107.

1

The American Cancer Society and Support and Self-Help Groups

Definition of Groups

The guidelines presented in this book focus on two types of groups: support groups and self-help groups.

Self-Help Groups

Self-help groups are made up of individuals and/or their family members who meet and function primarily without the guidance of a mental health professional. In self-help groups, the members share the responsibility for leadership. The continuity and consistency of these groups vary according to their structure.

Self-help groups for people with cancer and their families emerged from the larger self-help movement that began with Alcoholics Anonymous in the 1930s. That movement rekindled interest in the age-old practice of providing mutual aid through social support. It eventually spread and now includes not only groups formed to deal with problematic behavior, but also groups for enhancing personal growth, managing a common stress or predicament, or defending the rights of a minority and normalizing its status.[3]

There are many kinds of self-help groups and many different models for this type of support. Both the National Coalition for Cancer Survivorship (NCCS) and Candlelighters Childhood Cancer Foundation are examples of national groups with chapters in many locations. Most self-help groups arise when an individual or a group of individuals identify an unmet need in the community and organize a group to address it. Some are highly organized and have a national structure (NCCS), while others are strictly local. Coordination of a group may be facilitated by its members or by a professional.

Support Groups

Support groups are comprised of individuals and/or their family members who meet under the leadership of a health care or mental health professional. Interest in support groups for people with cancer and their families started to grow in the mid to late 1970s. As interest in support groups increased, health care providers learned that these groups were not intended to be substitutes for treatment but represented a positive way for people to use human relationships to work on problems common to the cancer experience.

A variety of health care providers and organizations, including the American Cancer Society (the Society), became interested in sponsoring support groups once it became apparent that participation in such groups could help alleviate the psychological distress and social isolation experienced by many people affected by cancer. In the past 10 to 15 years, various professionals have organized support groups to provide a formal means by which individuals in similar circumstances can share ideas, feelings, and coping strategies. Many support groups also include an educational component, featuring speakers who address certain medical or psychosocial topics followed by group discussion. The Society's I Can Cope® series is an example of a support/education group.

Some sponsoring organizations prefer the professionally led group model, primarily because of the complexity of many of the psychosocial issues involved in group support. In addition, such programs tend to ensure continuity and a high standard of service. Experience with professionally led support groups has spawned a different idea of group leadership, one that focuses on facilitation and sharing rather than directing. This concept of leadership is consistent with the idea that the members of a support group are responsible for determining the group's agenda, norms, content, and structure. It is also consistent with the belief that persons living with cancer are in charge of their own experience and know, better than anyone else, what they need.

Support groups are not to be confused with therapy groups. The latter focus on change in interpersonal style, while support groups focus on mutual aid and education (formal or informal). Support groups are therapeutic in that they help people to find relief from emotional stress but do not attempt to change behavior.

2

Group Characteristics

Types of Groups

Self-help and support groups vary in size and composition. The needs of the potential participants often determine the most appropriate type of group to organize. For example, women who have had a mastectomy might feel more comfortable in a group of their own, while a group for people undergoing chemotherapy might include both men and women with any type of cancer. Groups are either heterogeneous or homogeneous.

Heterogeneous Groups

Heterogeneous groups are made up of members with widely varying characteristics. They include people with different cancer diagnoses and/or their family members or anyone else affected by cancer. Such groups may be comprised of persons with a cancer diagnosis of any type, family members or friends of individuals with cancer of any type, or a combination of people with all types of cancer and their families and friends.

Advantages. Because heterogeneous groups are open to anyone, the pool of possible members is large. The diversity inherent in such groups allows members to see people in different stages of the cancer experience and to learn how others have dealt with various aspects of the illness. Group members who doubt their ability to cope can benefit from the advice, encouragement, and inspiration offered by others.

Disadvantages. Achieving cohesiveness and cultivating an atmosphere of supportiveness and mutual aid may be difficult. Members of an extremely diverse group may have little in common except a diagnosis of cancer. Individuals who are in the early stages of illness might be frightened by seeing persons in more advanced stages.

Homogeneous Groups

Homogeneous groups are limited to people who have something specific in common. For example, they may share the same diagnosis or stage of illness, the same age or ethnicity, or be undergoing the same type of treatment. Homogeneous groups may also comprise healthy persons who are at high risk to develop cancer or those who are bereaved.

Advantages. The more people have in common, the faster they form a bond with each other and feel a sense of belonging to a group. Since all members of a homogeneous group have similar interests and concerns, facilitators for these groups can provide more detailed information about a specific type of cancer or treatment. Homogeneous groups also enhance a member's sense of safety when delicate issues are discussed. For example, a woman recovering from a mastectomy might feel more comfortable discussing sexual or body-image issues in a group composed only of other women recovering from mastectomies.

Disadvantages. Creating and staffing a wide variety of specialized, separate homogeneous groups may not be possible if staff, facilitators, time, or resources are limited.

Whether or not it is possible to form a homogeneous group depends on the size of the target population. For instance, the pool of potential members in a cancer center will be larger than that in a community setting. Even in such a large population, finding enough people with a common characteristic (e.g., persons in their early 20s who are interested in a young adult group) will not always be possible. Conversely, if the number of potential participants is quite large, separating them into smaller, more specific groups may be beneficial. Suggestions for homogeneous groups include:

Specific cancer sites. Individuals with the same type of cancer (e.g., prostate), family/significant others of persons with the same type of cancer (e.g., wives or partners of men with prostate cancer), or a combination of such people (e.g., men with prostate cancer and their wives/partners).

People living with cancer often prefer to join groups that are specific to their own type of cancer. They may not understand that all people affected by cancer, regardless of the type, struggle with many of the same problems. If a certain site-specific group cannot be organized or is unavailable, advise those who wish to join to attend one or two sessions of an existing group so they can make an informed decision about participating in a more diversified group.

People living with cancer often prefer to join groups that are specific to their own type of cancer.

Stage of illness. Persons whose cancer is newly diagnosed, those who are currently receiving treatment, persons with a recurrence, those receiving palliative care (e.g., those who are undergoing radiation to relieve symptoms, not to cure), or persons in remission.

Specific age. Children, young adults, or elderly persons with cancer; or children of persons with cancer. A group of this type can address issues with which people are struggling within the context of their own age group or developmental stage. For example, elderly people might prefer to be grouped together rather than trying to relate to the dating experiences of young adults with cancer.

Specific culture/ethnicity. African Americans, Hispanics, Native Americans, or other groups. Certain issues are culturally sensitive and may be more comfortably discussed among people with the same cultural or ethnic background. An individual's cultural or ethnic identity can also dictate what type of meeting is most helpful. For example, some groups may prefer a format of talking and discussion only, while others prefer talking while working on a project. (For further discussion of cultural groups, see chapter 4.)

At-risk population. Daughters of women with breast cancer or family members of persons with colon or prostate cancer.

Bereavement. Persons who have lost a loved one to cancer.

Gender-specific. Men or women only. These groups also tend to be site-specific. Men may prefer a very structured program with a clear agenda and time frame. Formal presentations on topics related to cancer with a question and answer period work well. The Man to Man® group for men with prostate cancer is one such example. Gay men or lesbians might share issues more comfortably if they are grouped together.

Long-term survivors or persons who have completed treatment. Individuals struggling with long-term complications of treatment or those who are having difficulty reestablishing themselves as someone who is no longer sick.

Caregivers. Family members or friends of people with progressive or terminal illness.

Specific treatment method. Persons undergoing bone marrow transplant, radiation, chemotherapy, or participating in a clinical trial.

Structure

Support and self-help groups need structure. Members want to feel that they are part of an established group and want to know what to expect from meetings. The intended purpose of a group can suggest its composition. For example, people currently undergoing chemotherapy might prefer a group that is limited to chemotherapy patients and lasts only a certain number of weeks. On the other hand, a group of survivors trying to put their cancer into perspective might have meetings that are open for anyone to attend at any time, depending on their needs.

Consider the following options when determining the structure of a group:

Open Membership or Open-Ended Groups

Groups with this structure are open to people with any type of cancer, including their family and friends. The group may be ongoing with no established ending point, or it may be time-limited. Although attendance may fluctuate from meeting to meeting, a core group usually attends with some regularity, and these individuals tend to develop close personal ties.

Advantages. The advantages of groups with open membership are similar to those associated with heterogeneous groups. Since they are open to anyone, open meetings offer a large source of possible members. The diversity of open groups allows participants to see others in different stages of disease and how people cope with various aspects of the cancer experience. New members may join an open group at any point in time, and this flexibility makes the group more available and helpful to someone who seeks immediate attention.

Disadvantages. Over time, members of the core group may undergo changes that alter the atmosphere of the meetings. They may feel more stable medically and are no longer in a state of crisis. The tone of meetings may become more social, and participants may resist accommodating newcomers who may be experiencing the intense emotions often associated with earlier stages of cancer. Other members may become a disruptive influence on the group process or need individual help. In addition, locating leaders who are willing to make an ongoing commitment may be difficult. Maintaining an open group can be a daunting task, and continuing marketing may be necessary.

Leaders new to group facilitation may find open-ended groups more difficult because of the many unknowns. Participants may feel that they are always "starting over" as new members arrive.

Closed Membership or Time-Limited

Membership in closed or time-limited groups is limited. The same people come each week, and the number of meetings is predetermined. Meetings typically continue for six to 12 weeks, and new members usually are not invited to join after the second session.

Advantages. Many people are more comfortable entering a group cycle that has a definite end point, preferring to have control over their commitment. Likewise, potential facilitators may be more inclined to commit to a time-limited group. Participants in a group with an established membership usually get to know and trust each other faster than they would in an open group; problem solving may be easier among people with an ongoing relationship. Closed groups offer some flexibility for the facilitator. An experienced leader can suggest a discussion format, while someone who is inexperienced can start out by inviting guest speakers.

Disadvantages. People who want to join the group must wait until the next starting point. Turning them away can be difficult, especially if there is no place to refer them. On the other hand, trying to organize this type of group may not be practical in a sparsely populated area, because a large enough group of committed participants may not be available.

Combined Open-Ended and Closed Membership Groups

These groups are open-ended, but membership is limited to persons with a specific diagnosis (e.g., prostate or breast cancer).

Advantages. Because anyone with a particular type of cancer can join the group at any time, the number of possible members is large. The commonality of having the same cancer site allows members to identify more easily with each other's experiences, medical treatment, and emotional reactions. Although the composition of the group may change from meeting to meeting, a dedicated core group usually forms. (For further discussion, see Groups for Specific Cancer Sites—Advantages, chapter 4.)

Disadvantages. Groups that are limited to individuals with a specific diagnosis can sometimes be too focused on site-specific issues. Facilitators of these groups may over-identify with the participants or have trouble separating themselves from the group members, and this may cause anxiety for everyone. In such situations, the facilitator may become overwhelmed, especially if a group member dies. Again, locating leaders willing to make a commitment to an ongoing group may be difficult, and forming a site-specific group may not be possible in every community. (For further discussion, see Groups for Specific Cancer Sites—Disadvantages, chapter 4.)

Format

Group meetings can be either structured or unstructured.

Structured Meetings

Structured meetings have a set agenda. Either the facilitator or an invited guest speaks about a topic that has been predetermined, preferably based on input from group members. The presentation is usually followed by a question-and-answer period and group discussion. Structured groups tend to be educational in nature and are well suited for providing specific information (e.g., what to expect from radiation therapy and how to manage the side effects). The Society's I Can Cope program and the Man to Man group are examples of structured meetings.

Unstructured Meetings

Unstructured meetings have no set agenda, and members discuss whatever topics arise. Some people prefer this type of group because it encourages spontaneous discussion and exploration of various issues. In general, unstructured groups function more effectively with a trained facilitator who is skilled in understanding and managing group dynamics.

Size

According to Cella and Yellen,[1] the best size for a support or self-help group is a minimum of five and a maximum of 12 people; the most effective group comprises six to eight persons. Size-limited groups are large enough to permit good interaction, yet small enough to allow members to work on individual problems and to give everyone a chance to participate.

Attendance will fluctuate, and attrition is to be expected. Some people will drop out after the first session, and others may become too ill to attend. It is important not to overcompensate for attrition, however. If all members come to every meeting, the group will be too large to allow time for each member to speak. On the other hand, a group that dwindles down to one or two members is no longer viable and will not be cost efficient or as helpful to the participants as a larger group. Limiting membership to 10 to15 persons usually results in a workable number of attendees.

Groups may also be quite large, sometimes with 30 members or more. Large groups generally require a structured format, including a presentation by a speaker followed by a question-and-answer period. Members may break into smaller groups afterward for sharing and support. Facilitators of large groups have the responsibility to frequently assess the needs of individual members, so that participants who need more attention or assistance with a specific problem can be directed to another source of help.

The best size for a support or self-help group is a minimum of five and a maximum of 12 people.

Frequency, Length, and Location of Meetings

The frequency of meetings will depend on the needs of the participants and how much time the facilitator can devote. Weekly meetings help members feel like a group faster. Monthly meetings can make members feel disconnected, creating a need to get reacquainted at each meeting and detracting from the continuity of the group. Meeting twice a month is a compromise that helps the group stay on track while allowing for smooth integration of new participants.

An appropriate cycle for time-limited groups is six to 12 weeks. A commitment to this length of time is convenient for most people. Both open and closed meetings should last about 90 minutes. This amount of time permits people to settle in and exchange ideas, feelings, and thoughts with each other.

Meetings should take place in an atmosphere that is conducive to communication. Hospital-based meeting rooms can be uncomfortable for group members because of the constant reminder of disease or treatment. In addition, hospitals can represent an unfamiliar area where potential participants might feel intimidated, a loss of control, or a lack of trust. Other choices include a room in a church, library, hotel conference room, or a Society office, if space permits.

Consider the following guidelines when selecting a location for meetings:

- The facility should be easy to find. It should be located close to a major highway or public transportation. Nearby parking should be available, and members should be informed of any parking fees.
- The room must be large enough to accommodate the group but small and private enough to create a feeling of comfort. If possible, living-room style furniture should be used, with chairs that can be grouped for easy conversation. Hot water for coffee and tea adds to the informal, conversational atmosphere.
- Free babysitting may make attendance possible for people who would otherwise be unable to come.

- Each session should take place in the same room because a familiar space helps create group cohesiveness. Meetings should be scheduled at times when noise and distraction from other groups will not be disruptive.
- A space where there is no fee is preferable, and the possibility of any hidden charges (e.g., a donation for heating in winter, fees for the custodian to open and close the room, etc.) should be investigated.
- Restrooms and the meeting room itself should be easily accessible to everyone, including those who are elderly or disabled.
- The meeting facility should provide the facilitator with either a key or an alternate means of entry.
- The facility should be situated in a well-lit, well-trafficked area. Good security is essential.

Norms and Guidelines

It is the facilitator's job to establish certain norms or guidelines for the meetings, regardless of how the group is organized. Setting boundaries lets members know what to expect from the group and helps them feel more comfortable with each other. Discuss the ground rules at the very beginning of the meeting cycle to help members reach a consensus about the rules. People with limited experience may feel uncomfortable in the role of authority figure, but it is the responsibility of the facilitator to help people feel safe. Group members will appreciate that protection.

Facilitators who are starting a new group should keep the following guidelines in mind:

- **Establish confidentiality immediately.** Members must feel safe enough to talk honestly and openly within the group. Explain to them that whatever is discussed in meetings will not be shared with anyone outside the group. Make it clear, however, that there is an exception to this rule: confidentiality cannot be maintained in the face of self-destructive or suicidal behavior. When suicide is a risk, you have the responsibility to talk privately with the person involved and to communicate with his or her family. A suicidal patient is frightening to others, particularly those who are new to the cancer experience and are questioning their own ability to cope. Group members need to know that suicide is rare among individuals who are being treated for cancer, and that suicidal people usually come to the cancer experience with preexisting problems.

- **Discuss what confidentiality means for both the facilitator and group members.** Facilitators must agree not to release the names of participants or discuss with anyone else what specific individuals are talking about within the group. Group members must also agree to protect the privacy of everyone, even when talking to their families and friends about their experience in the group. Encourage participants to agree to a contract of confidentiality at the beginning of a meeting cycle. Such an agreement will reassure people that it is safe to talk about whatever is troubling them.

- **Professionals in a hospital setting may need to give verbal or written feedback to the patient's treatment team regarding how the patient is functioning in the group** (see appendix C). If that is the case, group members need to give permission for this to happen. As in the previous discussion, the only exception is with people who are at risk for suicide.

- **Urge members not to interrupt each other.** Giving all members the opportunity to express their thoughts and concerns without being interrupted promotes mutual respect and helps members feel that what they have to say is important. Avoid letting one person monopolize the meeting to the detriment of the others. Invite quiet members to participate and share their feelings, but let everyone know that they do not have to speak until they are ready to do so.

- **Ensure that meetings start and finish on time.** Setting boundaries helps members feel secure. Inexperienced facilitators may have trouble ending a group session, especially if the discussion is going well and people are really connecting with each other. Try to resist the impulse to let group members control the process, however. A schedule that is established and enforced allows group members to make arrangements at work, with babysitters, or with family members.

Setting Goals

Many people, especially those with no experience with self-help or support groups, may feel apprehensive if they do not know what to expect during meetings. Setting goals and thus providing direction often can alleviate such anxiety. Goal-setting also serves to reassure members that the group belongs to them, and that they can count on you to keep the group focused on what is important to them.

Most experts agree that the general goals of a support or self-help group are to:

- provide encouragement and reinforcement to members
- alleviate feelings of isolation
- cultivate mutual respect among members
- share information that can help people cope
- explore problem-solving strategies
- discuss the advantages and disadvantages of various coping strategies offered by participants or the facilitator

The composition of a group will determine its specific goals. For example, a group for daughters of women with breast cancer and one for men with prostate cancer will have different goals.

Roles

The formation and maintenance of a group usually involves several people. When members share various aspects of the leadership role, the group is better able to realize its purpose, which is to provide support and establish an atmosphere in which members feel welcomed, accepted, and supported by one another.

Professionals

Professional facilitator. The role of a facilitator is to promote cohesion, develop a safe environment, help group dynamics evolve, offer generous reinforcement, foster stress reduction, and give information. (Leadership skills are discussed in detail in chapter 3.)

Professional consultant/advisor. Groups that are not led by a professional facilitator should try to have access to one. A professional consultant can help identify emerging problems in the group, establish a plan for dealing with difficult or complicated issues, and give advice about promoting a positive, supportive atmosphere. Even trained facilitators can benefit from input from a peer. A professional advisor can function as a consultant and a sounding board for group leaders who need help with certain issues and questions. Ideally, clinical supervision should be available for every group leader, especially those with limited or no experience.

If you are a professional with limited experience in group facilitation, request assistance from your sponsoring organization, stressing the need for the entire group to have a successful experience. The sponsoring organization certainly will want members to have a positive group experience because that generates good will for the institution. If the organization cannot provide a supervisor or consultant, it might be willing to pay a consulting fee to someone in the community who is experienced with groups. If that is not possible, ask a colleague to be available on an informal basis. A confident facilitator can provide a richer experience for the group.

Non-professionals

Non-professional facilitator. Volunteers can serve as non-professional facilitators, providing structure and helping maintain group focus. Many natural leaders are available for facilitating support or self-help groups. These are people who, without any formal training, understand the purpose of a group and can help it achieve its goals.

Non-professional facilitators also need support and advice and should identify another person, either a professional or someone with more experience, to act as a troubleshooter. For example, an inexperienced leader may not know how to help group members who are experiencing a severe degree of stress or how to manage someone whose behavior is disruptive to the group. An experienced consultant can suggest interventions that will help in such situations without making anyone feel rejected or judged.

Co-facilitator. Some groups can benefit from having two facilitators. Co-facilitators can share leadership tasks as well as expertise. For example, one leader may be very knowledgeable about the physical aspects of the disease, while the other has expertise in group dynamics. In groups comprising persons of a particular ethnicity or culture, one facilitator may be a member of the ethnic group. (This is discussed in further detail in Ethnic/Cultural Groups, chapter 4.) Because of staffing constraints, co-facilitation may not be possible for professional facilitators working in a hospital setting, in which case it is even more important to identify a consultant to call upon if problems arise.

Group Members

As in any group, members of support and self-help groups often help each other as a natural function of their participation. The most successful self-help and support groups are those in which virtually all the help obtained by members comes from their peers and not from the leader(s). If you are an inexperienced or non-professional facilitator, you may have difficulty appreciating and fostering this, especially if you are unsure of your skills and want positive feedback from group members to reinforce them. As is true with individual counseling, the goal of group counseling is to empower members to solve their own problems. You will come to appreciate the process of people learning to cope by sharing wisdom and experience with each other.

Process

Process is what is happening between people—the roadmap, if you will, of how the group is getting from one point to another. Some components of process are:

- how something is said, not just the words a person uses
- the feelings that accompany language
- a person’s tone of voice
- behaviors that signal a person is anxious
- avoiding certain topics or changing the subject
- avoiding meetings where people are likely to be discussing difficult issues

These verbal and nonverbal behaviors can tell a trained facilitator a lot about what is going on with people. For example, people who frequently joke during meetings may be using humor to cover up their anxiety. When a group member is being disruptive, determine what the person is trying to accomplish by the behavior before deciding how to intervene.

Both professional and non-professional facilitators must be aware of the group process in order to help members support one another. The following strategies can be used to support the group process:

- Identify what is universal in everyone's experience and common to them as people. ("Have others felt the same way?")
- Encourage expressions of emotion and the relief that usually follows. ("How is it for you to have shared such painful feelings?")
- Encourage members to be supportive and helpful to each other. ("Can anyone else suggest a way out of this dilemma?")
- Provide information and advice. ("I think Medicare covers that service. Does anyone know how to find out?")
- Instill hope. ("I know others must have felt this bad. How did people start feeling positive again?")
- Provide opportunities to model or imitate the positive coping techniques of others. ("Let's role play another way of communicating with your doctor.")
- Foster group cohesiveness. ("I'm very touched by how this group responds when one of you is in trouble.")
- Develop a common sense of purpose and meaning. ("What do you want for yourselves as a result of attending this group?")

Phases

As noted by Wasserman and Danforth,[2] support and self-help groups are likely to undergo developmental phases. This means that certain events, feelings, and behaviors characteristic of the group are predictable and reflect the group's status at a specific time.

Generally, phases can be thought of as beginning, middle, and end. (See chapter 3 for a discussion of leadership tasks during each phase.)

These phases do not always occur in the same order; some phases may seem to occur simultaneously or sometimes even to recur. In addition, these phases are more predictable and likely to occur in closed groups. In open groups, phases may be less obvious or predictable because members may change from session to session.

…certain events, feelings, and behaviors characteristic of the group are predictable and reflect the group's status at a specific time.

Beginning Phase

During this phase, group members learn to trust the facilitator and each other enough to feel safe about openly discussing their fears and concerns.

During the beginning phase, members can be expected to:

- Find common ground. Members realize that others have had experiences similar to theirs and that everyone is "in the same boat."
- Seek information. Members inquire about and respond to practical information and/or alternatives in dealing with their problems.

Middle Phase

Most of the work of the group occurs during this phase. It is during this time that the group is most likely to achieve cohesion, to give and receive support and mutual aid, to become open to self-examination, to redefine the meaning of certain experiences, and to try new ways of coping. Events that occur during this phase indicate whether the group is effective in meeting the needs of its members.

During the middle phase, members can be expected to:

- Become open to self-examination. Members gain a greater self-awareness and self-acceptance as they begin to recognize their own psychological and emotional needs.
- Achieve mutual aid. Members share their experiences with each other and are giving help as well as receiving it.

End Phase

This phase is a time of transition, and members are likely to feel ambivalent about it. Many kinds of endings occur in self-help and support groups. When a member leaves the group, those remaining might feel happy or sad depending on the circumstances of the departure. As the end of the group cycle approaches, members may express feelings of happiness, sadness, anxiety, or relief.

During the end phase, members can be expected to make transitions. They may arrange for or continue to have informal contact after the group ends. Members who are inclined to extend contact should be encouraged to do so. Some members of a group that is ending will want to continue reaching out to other people who are coping with similar cancer-related issues. Refer these people to the local Society office, which will help them explore opportunities for volunteering, such as Reach to Recovery®, a one-to-one volunteer visitation program for women with breast cancer, or Road to Recovery,℠ a volunteer program that provides assistance to cancer patients who need transportation to and from treatment.

Themes of Discussion

Regardless of the type or structure of the group, certain themes are likely to emerge at meetings. If you know about these themes in advance, you will be able to address them more easily.

Cella and Yellen[1] found that the most common themes of discussion include:

- the emotional impact of illness
- the meaning of illness
- family difficulty
- problems of intimacy
- a sense of isolation/stigma
- role changes

- cancer-specific concerns
- negotiating the health care system

Regardless of whether you are a professional or non-professional, you should explore your personal reactions to some of these themes before organizing a group. If you know you will be uncomfortable discussing sexual intimacy, for instance, you must acknowledge the fact that your own reactions might inhibit the group process and then determine an appropriate way to handle such situations. Facilitators who do not feel competent discussing specific disease-related issues or ways to negotiate the health care system should consult with a more experienced person. Again, remember that people living with cancer are the experts about its impact on their lives.

Non-professionals or professionals with limited experience in oncology or group facilitation may be unsure about how to start putting a group together. This and other books will be helpful, but inexperienced people should also consider seeking advice from an established facilitator. Most people involved with helping individuals with cancer are very generous and are happy to talk about what has or has not worked for them, such as putting young adults and older people in a group together. Professionals might simply consult with their colleagues at the hospital. Non-professionals can seek guidance from hospital personnel and perhaps identify a professional that could act as an advisor for the group. The Association of Oncology Social Work is a valuable resource and can be contacted at their central office (847-375-4721) or Web site (www.aosw.org). Oncology social workers have experience with all types of groups, and part of their mission is to help individuals find appropriate support services. Members of the organization can provide guidance and may be able to identify someone in the area who could be helpful.

References

1. Cella DF, Yellen SB. Cancer support groups: the state of the art. *Cancer Practice.* 1993;1:59-60.

2. Wasserman H, Danforth HE. *The Human Bond: Support Groups and Mutual Aid.* New York, NY: Springer; 1988.

3

Group Leadership/Facilitation

Criteria for Group Leaders

The qualifications for being a facilitator of either a self-help or support group are the same, but every person brings different interests and experiences to the task. An interest in the cancer experience and its effect on people is an obvious prerequisite but is not the only element necessary for success. Once you have made a decision regarding the structure, format, frequency, and location of the group (see chapter 2), evaluate your existing skills and knowledge and determine what you will need to get started.

For Self-Help Group Facilitators

Most people who become interested in facilitating a self-help group have had personal experience with cancer. Survivors may develop a strong desire to help other people who are living with cancer—to give something back or to use their own experience in a positive way. People with cancer acquire a great deal of information about the disease itself and its treatments, as well as personal knowledge about facing adversity. It is a credit to the human spirit that a medical crisis often fosters personal growth rather than despair. Of course, the world will occasionally seem very bleak to people undergoing cancer treatment; the roller coaster of high and low emotions can be exhausting for even the strongest person. However, many people reach a point where they feel that the worst is over, and they are ready to move on with their lives. It is often at this time that cancer survivors consider the possibility of helping others.

If you intend to lead or facilitate a group, you should be aware of the emotional highs and lows that can accompany this experience. Group facilitators often derive gratification and pleasure from their role as a helper. Satisfaction comes from participating in a process in which sadness can be eased and people inspired by the generosity and kindness of group members. Being involved with others as they discover new ways to solve problems is also fulfilling.

You may not be prepared for the feelings of sadness that can emerge as your relationship with other members of the group deepens. Being a witness to the pain of others can be upsetting for anyone. Cancer survivors who have been optimistic and progressing well emotionally may become anxious and uncertain when confronted with persons who are not as far along in the recovery process. These experiences can stir up memories for the survivor and result in revisiting the upheaval caused by a cancer diagnosis or treatment. If you are a former patient who has chosen to facilitate a cancer support or self-help group, you should be alert to these issues and not become alarmed when emotionally challenging events occur. However, it is also important to avoid becoming immobilized by memories of the past.

An obvious caution for potential facilitators is to wait a sufficient amount of time past the point of your own diagnosis before taking on the responsibility for a group. This period of time may be a year for some people or longer for others, depending on your personality, resources, and personal experience with illness. For example, the aggressiveness of treatment varies among different types of cancer, and some people feel the side effects of cancer treatment more intensely than others do. In addition to this temporal and psychological distance, facilitators also need their own support system. Such a system can be a forum for sharing the personal impact of being a group facilitator and may include family, friends, or other cancer survivors who are not involved in the group.

For Cancer Care Professionals

The major difference between professional and non-professional facilitators probably is the advantage that formal education can bring to the task. Social workers and nurses who specialize in oncology usually have taken courses in areas of human behavior. Such courses, in the form of either graduate studies or continuing education, offer a theoretical underpinning of knowledge that is helpful when working with people who are experiencing a medical crisis. If you think you have not had sufficient education in the area of group process and dynamics, consulting this book and other references[1, 2] may be useful.

The work of a facilitator involves personal risk-taking on an emotional level.

The work of a facilitator involves personal risk-taking on an emotional level. Like anyone who facilitates a cancer support or self-help group, professionals who do so also need support; this is especially true for people with limited oncology experience. Facilitating the group process may seem more complicated than working with individuals. In order for everyone to get the most from the group experience, you need to find ways to deal with your own feelings so you can be emotionally available.

Even if you have been in the field for many years, you can probably remember the difficulty of maintaining some distance from the experiences of your patients. It is not unusual for oncology social workers or nurses to imagine a cancer diagnosis of their own, to dream about their patients, or to spend endless hours working in an effort to overcompensate for their own vulnerability. Such reactions come with the territory in oncology, but persons who are excessively affected may need help dealing with the personal impact of their work.

Support can take several forms, including clinical supervision, continuing education, or advice from peers with more group experience. Compared with a cancer survivor who is acting as a facilitator, a professional who is leading a group probably has greater access to institutional supports. If guidance or clinical supervision cannot be provided by an institution, you should find and make use of other resources.

To summarize, in addition to self-awareness, the successful group facilitator should have the following qualifications:

- be people-oriented
- have education or training in group facilitation
- have a working knowledge of group process and dynamics
- have the ability to act as a role model for participants and maintain objectivity

- demonstrate a good working knowledge of community resources
- be able to commit to leading the group for a predetermined period of time, usually six to 12 weeks
- clearly understand the difference between group psychotherapy and group support (psychotherapy deals with personality change while support groups do not)

Group Leadership/Facilitation

In any self-help or support group, all members are regarded as equals, with each person having an important contribution to make. Commonality of purpose is necessary so members can bond more easily and benefit from sharing experiences. A successful group needs someone to make sure meetings run smoothly and help it accomplish its purpose. This person does not direct the activities of the members but facilitates or guides them based on the intended direction of the group and how well it is meeting its goals. In this book the terms facilitator and leader are sometimes used interchangeably, but the emphasis is on facilitation. The leader of a support group does not attempt to control the process but rather ensures that it takes place within a supportive environment.

Leadership Roles

Self-help groups may have a designated leader, or all members can share leadership responsibilities. The leader may be a cancer survivor who initiated the idea of the group or a cancer care professional; the sophistication and background of leaders will vary. In general, however, support or self-help group facilitators have the following roles and responsibilities:

- to ask open-ended questions to encourage discussion; to keep the conversation focused
- to guide the discussion toward topics determined by group members rather than imposing a structured format
- to summarize the content of the discussion during the meeting and at its conclusion
- to suggest possible alternative solutions to problems

- to help members avoid focusing exclusively on negative feelings
- to foster a caring atmosphere in which all feelings and emotions are accepted; encouraging participants to be honest and to respect each another
- to intervene in an appropriate, supportive way when members demonstrate difficult or disruptive behavior
- to monitor the reasons why members miss or stop attending meetings; make referrals to more appropriate services, if necessary
- to invite members to follow up with one another without pressuring people into returning to the group if they do not wish to do so

Non-professionals with minimal or no experience facilitating groups may be overwhelmed by the responsibilities of leadership. These feelings may be especially strong for leaders who have recently undergone cancer treatment themselves. If you are faced with such a situation, attempt to identify a professional who might consider acting either as a consultant or a co-facilitator for the group. Ongoing access to a professional adviser can be very useful when dealing with difficult issues and/or challenging group members. The local Society chapter might be able to identify a professional who could help your group get underway. If a professional group facilitator is not available, the Association of Oncology Social Work or the Oncology Nursing Society may be able to help. Cancer care professionals without sufficient experience in facilitating groups may also seek assistance from these organizations.

Leadership Skills

The needs of individuals in self-help and support groups vary tremendously, and leadership/facilitation must be tailored to the requirements and goals of each group.[3] Developing good leadership skills is a long process that requires experience, education, and energy. New facilitators will undoubtedly make some mistakes, but it is far better to take the risk of organizing a group than to focus on what could go wrong. As discussed in chapter 2, a professional consultant can help an inexperienced leader plan for dealing with problems and getting through difficult times.

Help people join together and experience how similar their emotions and issues may be.

If you are planning to set up a support group, the following good leadership tasks should be considered:

Promote a sense of togetherness (cohesion). Help people join together and experience how similar their emotions and issues may be. Sometimes members challenge this sense of group cohesion by being critical or monopolizing. Attempt to balance or refocus the group if members display negative behaviors or the group needs to be redirected. Encouraging members to make decisions as a group will help them appreciate their similarities rather than focusing on their differences. It will also enhance trust in their ability to help one another.

Develop a safe climate. People need to know they will be accepted as they are. Leaders who mistakenly think their own role is getting people to change may frighten the group members. If a leader pushes for self-disclosure or tries to interpret an individual's behavior (as might happen in a therapy group), the member is likely to leave the group. People come to support groups for support, not personality change. After all, people often come to the cancer experience with enough doubts about themselves or their ability to cope. It is important that people feel comfortable participating in a group.

Keep your interpretations focused on the group (e.g., "It sounds like that makes people feel angry and vulnerable"), not on the individual. Humor can be helpful in diffusing some of the tension that may be aroused when groups deal with strong emotions. Because of the power of the emotions generated in a support group, the leader can sometimes become a symbol of the conflicts that members are experiencing. This phenomenon, called transference, can occur when a counselor or group facilitator is perceived as having more authority or power than the group members do. Transference can happen in any therapeutic situation when emotions become intense and might be more problematic for a non-professional group facilitator than for a professional in the same situation. A co-facilitator or professional consultant might be useful in these situations.

Help members support each other. Group members need to have a sense of what to expect in a support group; this is important in terms of having their own needs met and for their ability to help others. Because people may react to the stress of cancer by feeling overwhelmed or helpless, the facilitator should encourage behaviors that promote taking charge of problems and finding solutions. Members of groups that are responsible for their own agendas will feel a sense of ownership, and they will be able to support one another in problem solving.

A leader who can truly listen and relate to the emotions that are expressed creates a supportive environment in which people can gain strength from one another. This demonstration of empathy also teaches group members how to kindly respond and build their skills as helpers.

Reinforce the positive. In any group, the behavior of some members may become counterproductive to effective problem solving. For instance, an angry patient may take a provocative or demanding tone when discussing a conversation with his physician. Suggest that the group examine this style of interaction, perhaps by imagining what the physician's response might be. Dealing with anger is problematic for most people. Encourage members to investigate ways to express their need for information that might produce the desired result. Role playing is a technique that often contributes to effective problem solving.

By maintaining a positive attitude, the leader acts as a role model as group members learn to select the most productive approaches to dealing with their problems. An effective facilitator empowers members to feel less dependent, to handle any negative behaviors that participants demonstrate, and to feel that they have control over problematic situations.

Provide structure. The group leader must provide a structure within which the group process will occur. As discussed previously, important structural factors that symbolize a nurturing atmosphere include consistent meeting times, physical space that is comfortable and regularly available, and refreshments.

Group members naturally engage in a certain amount of social conversation, but it is the responsibility of the facilitator to keep the group focused on its goals. Socializing is appropriate at certain times, such as a special holiday luncheon, and you can provide or suggest a framework with which to balance the seriousness of the group process. Some group members may resist your efforts to establish boundaries and protect the group process, but any group must have structure and purpose in order to be most useful to its members. Resist any temptation to let go of the leadership role or, conversely, to become so rigid that people feel that the structure of the group is more important than their own needs.

Provide information. Facilitators should be well informed about cancer and the related psychosocial issues that will arise. It is not appropriate to dominate a meeting with medical information or advice, but it will be necessary to correct the misconceptions about the disease or its treatment that invariably come up. The same rule applies to psychosocial issues. For example, you might state that persons with newly diagnosed cancer do not invariably become clinically depressed. Encourage members to discuss their own experiences with sadness. Remember that although some problems have no clear-cut solutions, it is your responsibility to help members explore their feelings and ideas. Group members need the security of knowing that the leader is available as a resource.

How-To Skills

The tasks of recruiting and interviewing potential members, running meetings, and handling behavioral problems all require certain leadership and interpersonal skills. Although these skills can be taught, they will continue to evolve and become more refined as you gain more experience.

The following how-to skills are presented as guidelines for managing various situations. You should and will, however, develop a personal style. That style should not only be comfortable and effective for you but also flexible enough to adapt to the needs of the group.

How to Select Potential Members

Facilitators should contact or meet with potential members who wish to join the group. This interview is beneficial because it helps alleviate any nervousness the potential member has about entering the group and allows the facilitator to engage members in a personal way. By screening, you gain some insight into an individual’s needs and can assess his or her suitability for inclusion in a particular group. Because of their structure, closed groups and time-limited open groups offer a greater opportunity for screening compared with open groups. (For a discussion of open and closed groups, see chapter 2, Group Characteristics: Structure.)

The screening interview may take place either in person or by phone. The less screening you do, the more risk you assume. Screening not only prepares the facilitator for handling the unique characteristics of each group member, but it also helps identify people whose needs would be better met in a way other than the group. Arranging in-person interviews may be difficult or impossible for professional facilitators, especially those who are hospital-based, because of managed care and reimbursement constraints.

Whether the screening interview takes place by phone or in person, it is important to accomplish the following tasks:

- Determine whether the individual's needs are consistent with the goals and objectives of the group. For example, a group for long-term, disease-free survivors is inappropriate for someone with late-stage illness.
- Gain some insight into dominating or passive personalities and other characteristics that may affect the group's general effectiveness.
- Identify people who may have significant psychiatric symptoms (e.g., hallucinations, delusions, etc.) or a substance abuse problem. Refer them to the appropriate health care institution, mental health agency, or health care professional.
- Refer an individual who does not fit in with the stated purpose of the group to other resources.
- Encourage reluctant participants to attend one or two sessions to evaluate the group's usefulness to them. Sometimes referring them to a veteran group member will be helpful.

Remember that referring individuals for whom group support seems inappropriate to other resources is only one purpose of screening. The much more prevalent purpose is to learn more about incoming members in order to help them better. If a person needs to be referred elsewhere, be sensitive to how this gets communicated. Facilitators might say something like, "I'm concerned that because of the nature of your problem, you may not receive the kind of help you need from a support group," or

"Based on what is going on in the group right now, I feel that talking to an individual counselor might help you feel better quicker." Remember that you are the expert; screening someone out of the group may make you uncomfortable, but you know the group and its dynamics better than anyone else does.

How-To Skills at Various Phases of the Group Process

All groups go through phases, and the group cycle includes a beginning, middle, and an end. (See chapter 2 for a full discussion of phases.) Effective leadership skills vary according to the phases of the group.

The Beginning Phase

Establishing trust is the most important task to accomplish in the beginning phase of the group cycle. If this does not happen, the group will not get off the ground. To help establish trust:

Begin and end on time. Giving members boundaries helps them feel secure. Acknowledging that their time is important and valuable contributes to their self-esteem.

Use introductions and ice breakers. Some people, if not most, have never joined a support group before and are nervous about what to expect. Acknowledge their anxiety and applaud the courage it took for everyone to come to the first meeting. Be sensitive to people who appear to be frightened or overwhelmed by either their cancer or the group experience. Ask members to introduce themselves to the group and tell something about their own experience or what they hope to gain from the group, but only if they feel comfortable enough to do so. (The facilitator should attempt to keep track of this information.) Use of these strategies demonstrates that each person is important and will be listened to, shows members what experiences and feelings they have in common with each other, and establishes cohesion right from the beginning.

Help the group set ground rules. As discussed previously, ground rules represent the expectations members have of each other. Certain ground rules apply to all groups (e.g., confidentiality, respect), while others vary from group to group (e.g., food, no food). At the beginning of a group cycle, the basic ground rules (e.g., confidentiality, reaching consensus about decision-making) should be clearly stated so members know what to expect. Additional ground rules can be added or changed by the group at any time, as long as the group reaches a consensus.

Help the group define itself and set its goals. Except in the case of certain predetermined types of groups (e.g., an eight-week group for people with lymphoma), the beginning phase is the time to help members make decisions such as whether the group will be structured or unstructured, open or closed. It is also the time when the group should set goals and make sure everyone agrees with them. This process involves discussion, negotiation, and decision-making by consensus.

Provide structure. Once the issues and concerns of the members have been addressed, the facilitator can provide structure to the group by:

- Facilitating the group process, supporting members who wish to remain quiet while encouraging others to share their own personal experiences. Participants should be encouraged and supported but not pressured.

- Clarifying the agenda for each meeting, even if the structure of the group is purely discussion. The agenda will be determined by what the leader and the members have agreed is the group's purpose and by what has happened in previous meetings.

- Giving a brief presentation on a cancer-related topic or arranging for a guest speaker if the members request this format or if education is a goal. Such a presentation should be factual and should include a question-and-answer period. The group should agree to a designated period of time for the presentation and question-and-answer period and allow time for discussion and mutual support afterwards. Be sure to keep track of the time. People will be frustrated if the session must end prematurely, and a speaker who is not permitted to finish a presentation may be disinclined to return.

Helping members express their feelings and concerns enables the facilitator to shape the content of group meetings.

The Middle Phase

During this phase people share feelings and participate in the give-and-take process of mutual aid. Helping members express their feelings and concerns enables the facilitator to shape the content of group meetings.

How to develop content issues. The content of meetings is highly related to the group's overall purpose and goals. Content issues are essentially those that members want to discuss. These issues will change and evolve as the group process gets underway.

Some groups function well when the leader suggests specific topics, while others work well when members spontaneously determine the content. A suggested main topic may be discussed for the duration of a meeting, or a topic can be used only as an icebreaker to get conversation started. If a member brings up an issue that elicits strong group interest, encourage the others to share their own experiences, and give each person a chance to participate. Inexperienced facilitators who become frustrated when a discussion gets off track should ask group members whether they think the discussion is proceeding appropriately. The group can determine whether a real change of direction is necessary. Going off track may mean that people are uncomfortable with the main topic that is being discussed and need help dealing with their feelings.

How to help members share personal experiences.

- Give each person an opportunity to participate and share cancer-related experiences. Do not allow one person to monopolize or use the group for his or her own personal needs to the detriment of others.

- Avoid giving advice. Everyone experiences cancer in a unique way. No two people react to chemotherapy in the same way or have exactly the same disease process. People have their own coping methods, their own techniques for gaining control, and their own unique ways of relating to others about their disease. Remind participants to limit their input to first-person "I" statements rather than "you should" statements.

- Maintain a balanced discussion of coping mechanisms, but do not dwell on any one to the exclusion of others. For example, spirituality, humor, meditation, imagery, recreation, counseling, group support, relaxation techniques, reading, and distracting activities are all used as coping mechanisms. Each method can be important, depending upon the background and needs of the individual.
- Avoid oversimplifying or assigning blame, especially toward a hospital, physician, nurse, social worker, insurance company, etc. Even though an individual's anger is often justifiable given the current climate of health care services, focusing on the negative will not help anyone or give people what they need from the group. It is easy for the group to develop a negative, complaining tone if criticism of the health care system becomes the norm. To avoid this, do not deny the difficulties or the distressing feelings that accompany the cancer experience, but keep the focus on problem solving.

How to create a core group. In open-ended groups, the natural formation of a core group should be nurtured. A dedicated core group of members can form a unified, cohesive, trusting center; without it, the group will probably not continue. Members of the core group attend most meetings and can help newcomers feel comfortable. Try to prevent the core group from becoming a clique, however. The presence of a clique is difficult for the other group members, who may begin to feel as though their own needs are not legitimate. They may leave the group prematurely or with a sense of failure. Facilitators of groups in which a clique forms may believe they have failed to be effective leaders, which can be demoralizing.

When a core group starts to become exclusive, gently yet honestly confront the group about what is happening and help them identify the source of the difficulty. A confrontation of this type is likely to cause doubt and anxiety, but you are responsible to the group as a whole, not just its individual members. All participants will feel safe if they know they can count on you to manage the difficult moments that occur in all group situations.

Members may wish to exchange phone numbers and get in touch with each other outside of the setting of formal meetings. Recommend that members refrain from meeting as a group outside of the regular schedule until the formal group cycle has ended. Auxiliary meetings may dilute the role of the facilitator and interfere with the group process, resulting in two groups (one of which lacks the facilitator's guidance and objectivity) that are supposedly working on the same issues.

How to handle dropouts. In all groups, attrition and dropping out are normal occurrences and should not be interpreted as a sign that you are doing something wrong. People leave groups for a variety of reasons. They might stop attending because the timing of meetings is no longer convenient, because they have deteriorated physically, or because they believe they have gotten what they wanted from the group experience and no longer need to attend. Fear and group conflict are other reasons for leaving a group. Keep in mind that group participation is not right for everyone at all times. The personal psychology of certain individuals inhibits or interferes with their ability to participate in a group. Also, certain people can, in fact, manage the cancer experience without group support. For others, talking about a problem actually makes it worse. For people who want to help others, these realities may be difficult to accept. Rather than focusing on individuals who are not interested in support groups, try to concentrate on those who want and need your services.

Attempt to contact anyone who drops out of a group, particularly one that is closed or time-limited. Find out that person's reason for leaving, and ask permission to share the reason with the other group members. Departures should be acknowledged and discussed within the group. Members need to be reassured that they have not failed and are not responsible for another participant's decision to leave.

If you cannot determine why a person has dropped out, or if more than one member stops attending group sessions, you may want to talk with an experienced leader who can provide some insight and help clarify the group dynamics.

How to maintain momentum. The best way to maintain momentum within a group is to keep members actively involved. Encourage and enable participants to talk to each other and interact with the group. Help members feel comfortable by keeping meetings warm, friendly, and open.

All groups have two kinds of needs that must be met in order to maintain momentum and stay lively and effective.

- **Task needs.** Task needs get the job done; that is, they work toward fulfilling the group's purpose. Task needs are being met when members do things such as start the meeting on time, help keep it moving, provide information, summarize events, check to see if people agree, and offer a decision or conclusion for the group to accept or reject. Both the facilitator and the group members should check periodically to determine whether these needs are being met.
- **Maintenance needs.** Maintenance needs are things that members do in the group to help it work more effectively. Such tasks include encouraging each other, sharing personal feelings, adding humor to a meeting, supporting others who speak, or recommending a compromise when there is a disagreement.

Each group needs to find its own balance between its task needs and maintenance needs.

The Ending Phase

The ending of a group represents a transition. Endings can occur when a member or members leave the group, when the remaining group undergoes reorganization, or when the group itself is terminated. Help identify the meaning and impact of the ending for all participants so they can understand their own personal reactions in a larger context. People living with cancer or any catastrophic illness experience losses on many levels, and even the ending of a group can represent a threat on a very personal level. Endings that are not managed well by the leader or facilitator can cause unnecessary stress for both the person who is leaving and other group members.

Although you are not responsible for creating and maintaining a stress-free group, you do need to be aware of the vulnerability of group members and find ways to deal with it. This can be as simple as addressing the issue of vulnerability with group members and educating them about the emotions that often are churned up by endings. People living with cancer are not always in touch with their own reactions to events and can benefit greatly when a facilitator is able to normalize the stresses that group participation may provoke.

People living with cancer or any catastrophic illness experience losses on many levels, and even the ending of a group can represent a threat on a very personal level.

How to end a session. Every session should end on time. It is also important to follow certain procedures at the close of each meeting:

- Suggest that participants who want to converse socially are welcome to do so, but emphasize that the formal meeting is over.
- Assist with summarizing the meeting and with closure of the session's topic.
- Set plans for the next meeting to provide continuity.
- Make sure everyone has transportation home and that no safety issues need to be addressed, such as participants walking out to a dark parking lot or going outside alone.

How to end participation of a specific member. The context in which specific members leave the group will guide how to handle those particular endings. Depending on the circumstances surrounding it, an ending may be happy or sad. People may stop coming because they believe they do not need the group anymore, because they are sick, or because they died. Some groups develop a ritual that summarizes and symbolizes a loss in a way that allows members to pay respect to the person who has left the group, to acknowledge their own feelings of loss, and to move on. Such a ritual might be a moment of silence for a member who has died or the presentation of a funny photo collage of everyone in the group to a member who has decided to leave. Ask the group members what they think would help, and share with them ways in which other groups manage transition. Whatever ritual is used should be based on the experience of the group as a whole and have meaning for both the individual and the group.

How to end the group. Members of time-limited groups know in advance and agree that the group will end on a specific date. When that time comes, thank everyone for attending, and ask whether their expectations of the group were met. Also ask members about their current needs and whether they intend to be involved in a group in the future. Solicit feedback about the acceptability of the time, location, duration, and setting of the meetings. Inexperienced facilitators may be uncomfortable with these aspects of ending a group, especially if they are ambivalent about the success of the group or if their own feelings about endings are painful. Soliciting feedback from group members requires courage, but doing so can result in a richer learning experience for you, particularly if members are honest about what did or did not work for them.

Bringing an open-ended group to a conclusion may present special problems. New members may feel annoyed, while long-term members may feel abandoned by a group on which they depended. Explain why the group is ending, and discuss all the positive aspects of the group experience. Become knowledgeable about available resources so you can offer appropriate referrals to members who require or request additional support or counseling. Ending an open-ended group reinforces the reality of group limits: the group was ongoing but not forever, just like life.

Sharing Leadership Roles

Co-leadership is an effective technique for teaming an expert in group dynamics with a cancer expert (e.g., a health care professional with a cancer survivor). In a group for members of a particular culture or ethnicity, a co-facilitator of the same background as the members can bridge any language or cultural gaps that may exist if the other facilitator has a different background. (See chapter 4 for further discussion.) Co-leaders can share their observations of the group's needs and behaviors with each other. Sharing leadership is also a good technique for training inexperienced facilitators and is a practical means of receiving feedback about one's own effectiveness as a leader.

Finding cancer survivors with whom to share the responsibility for group leadership may be easier than enlisting a cancer care professional. Co-leadership may not be possible for these professionals because of the demands of the workplace and the institutional staffing constraints of recent years. People who are beginning their careers, however, should attempt to share group leadership with a more experienced colleague, whose input can be invaluable.

Identifying and Handling Problem Behaviors

At some point, every group leader encounters people who exhibit dysfunctional behaviors. Following are examples of persons with specific behaviors and suggestions for handling the problems that they may create.

The Monopolizer

The monopolizer attempts to tell his or her story during every discussion and wants to receive all of the group's attention. Although this type of behavior may initially be tolerated because of the generosity of the other members, it gradually becomes tedious and annoying. In addition, the monopolizer can seriously interfere with the group process, causing other group members to feel that they must compete for available time. If the situation is not recognized and addressed, the effectiveness of problem solving may be compromised, and the needs of all members may not be met.

Intervention: Start out by acknowledging the monopolizer's energy and subtly trying to redirect it. Humor may be an effective tool for dealing with a monopolizer (e.g., "Let's make a rule about how many times someone can tell his story.") For the benefit of the group, a direct confrontation with the monopolizer may ultimately be necessary. Try not to compete with people who tend to monopolize the discussion. Instead, determine appropriate ways to incorporate them into the agenda and maximize their potential contributions to the group.

The Help-Rejecting Complainer

The help-rejecting complainer complains all the time but refuses to accept any helpful suggestions. For this person, the need to vent is greater than the need to solve problems.

Intervention: Help the group confront the complainer, keeping the focus on a positive redirection of energy. Use yourself as an example to guide the complainer into taking constructive action. Ask the complainer to actively engage in problem solving by considering other sources of help. If none of these interventions are effective, refer the complainer elsewhere. Continued inclusion and tolerance of a complainer can be disruptive and demoralizing for other group members.

The Hostile Member

The hostile member inappropriately directs his or her hostility at other group members instead of using anger to mobilize constructive action. This type of person is probably hostile outside of the group as well.

Intervention: Take an active role to protect the group by clarifying group rules and norms. If the hostile member cannot or will not conform to the group rules, privately ask him or her to leave the group. Dealing with anger or hostility, especially when it is irrational, is difficult for most people. Once group members observe you setting limits, they will be better able to confront members with problematic behavior.

The Withdrawn Member

The withdrawn member rarely or never talks in the group. While silence does not always indicate a lack of participation, withdrawn behavior usually creates anxiety for other group members. They may wonder about the impact of what they are saying on the person who is withdrawn, or they may misinterpret a member's silence as being judgmental or critical of what is being discussed in the group.

Intervention: Encourage the group to include or engage the withdrawn member. Watch body language carefully to identify an appropriate time at which to invite the member to comment. For example, call on a withdrawn member to verbally contribute if his eyes light up during a certain discussion or if he nods while another person is speaking. Consider reintroducing ice-breaking techniques, such as asking each member to make a comment about a certain topic. Encourage participation, but do not demand it.

You may decide to have a private conversation with a withdrawn participant. Asking the member to tell you what he is getting from the group experience ought to give you the information you need. Some people simply are not comfortable talking in a group but gain a tremendous amount just by listening to others.

Members with Mental Health Problems

Members with mental health problems may be suicidal, psychotic, or deeply depressed. In general, these people do not function well in cancer support groups. They are usually very self-absorbed and unable to move beyond their own concerns in order to help others. Also, listening to the problems of others can be overwhelming for them. Other group members may be frightened by exposure to people with mental health problems. People who are new to the cancer experience have no way of knowing about coping strategies and might conclude that cancer treatment leads to severe mental health problems.

Intervention: Once you recognize that a member is experiencing serious emotional distress or is mentally ill, refer him or her to community mental health services. Inexperienced facilitators may have difficulty doing this, worrying that such a referral will be interpreted as rejection, and will thus exacerbate the problem. They may also be concerned that the intervention will elicit an irrational or angry response. Remember to keep the needs of the entire group foremost in your mind. It is the role of the facilitator to help a group be as productive as possible, and people with emotional problems can drain the resources of others.

The more important issue is that a cancer self-help or support group is not going to be helpful to someone who is suicidal, psychotic, or severely depressed. These people need to be evaluated for hospital admission and/or medication. It may be easier for professional facilitators than for laypersons to accomplish this kind of intervention because of the authority implicit in the role of a professional. Non-professionals who are having trouble dealing with this type of situation should seek advice from someone in the mental health field. People who are referred away from the group can be told that they will be welcomed back once their health improves.

Members with Special Needs

Members with special needs include those with hearing or visual problems, people with language difficulties, and individuals who are wheelchair-dependent.

Intervention: Try to make accommodations for a member's special needs, but be prepared to make tough decisions. The needs of the entire group take precedence over the needs of its individual members.

There are many other kinds of problematic behaviors as well as appropriate interventions. Readers who are interested in more detailed information should refer to Irvin Yallom's Theory and Practice of Group Psychotherapy.[1]

Dos and Don'ts for Group Leaders

Do

- participate
- provide information
- encourage everyone to talk
- be empathetic
- clarify people's feelings
- let group members explore strong feelings
- protect members from hostility
- support and balance opposing views
- prepare an agenda for discussion
- use structure to reduce members' anxiety
- acknowledge group tension
- use humor to reduce distress or bring people together
- encourage members to explore important questions

Don't

- take over
- lecture
- pressure people to talk
- focus on your own story
- prevent members from clarifying other people's feelings
- try to rescue group members from their strong feelings
- block appropriate expressions of anger
- take sides
- insist on an agenda
- use structure to reduce your own anxiety
- avoid tough issues
- use humor to distract or avoid difficult situations
- assume you must have the answers

References

1. Yallom I. *Theory and Practice of Group Psychotherapy.* 4th ed. New York, NY: Basic Books; 1995.

2. Pollin I. *Medical Crisis Counseling: Short-term Therapy for Long-term Illness.* New York, NY: W.W. Norton & Co; 1995.

3. Vugia HD. Support groups in oncology: building hope through the human bond. *J Psychosocial Oncol.* 1991;9:89-107.

4

Specialized Groups

This chapter examines support groups that are formed to help people who have something specific in common. Specialized support groups are created to address concerns, needs, and problems that certain people share, such as bereavement or childhood cancer. Some people have such specialized needs that they are unable to relate to other members of a generic support group. For example, candidates for a specialized support group might be people who have undergone bone marrow transplantation, those whose genetic testing has determined them to be at high risk for a particular cancer, or caregivers of people approaching end of life who are being cared for at home.

The viability of forming a specialized group depends on the size of the population being served as well as the availability of a facilitator with appropriate expertise. When sufficient numbers, interest, and need exist and a facilitator is available, formation of a specialized group can be appropriate and helpful.

Timing is an essential factor to consider when creating a specialized group, and facilitators should be sensitive to temporal factors in the cancer experience. It is important to understand that not all people who are invited to join a group are willing or ready to do so. People who are in a state of crisis following their initial cancer diagnosis may be too overwhelmed to benefit from group support, and it might be better to approach them after their treatment has gotten underway. On the other hand, people often feel adrift following the completion of treatment and miss the support they received from hospital staff during therapy. Therefore, a specialized support group for individuals whose treatment has been completed could be appropriate. Involvement in such a group might promote an easier transition back to their precancer lifestyle.

The same timing criteria apply to groups for people who are acutely bereaved. If they have been participating in a general cancer support group and their loved one dies, they probably would be better served in a specialized bereavement group. They probably will not have the emotional energy to respond to the needs of others whose loved ones are still receiving treatment.

Groups for Children

Groups for children can be based in a hospital, in the community, or at school. Children's groups differ somewhat from other groups in that a professional or professionally trained facilitator is required. A well-meaning adult who is not familiar with the many ways in which cancer and its treatment can impact children will have difficulty meeting their needs. Since specific phases of development greatly influence a child's response to illness, facilitators must be knowledgeable about child development. Even deciding which children should be grouped together depends on their individual stages of development. For instance, some 12-year-olds may be too immature to fit into an adolescent group and might be better off in a group with nine- and 10-year-olds.

Structure is very important for children's groups. Group sessions can be organized around particular topics, such as:

- What is cancer?
- Understanding emotions?
- What's different at school or at home?
- Changes in your parents' behavior.

Unlike adults, children cannot be expected to sit around a table and verbalize their feelings. Therefore, the group discussion (regardless of the topic) should be combined with structured activities (e.g., drawing, working with clay, games). This format helps children express themselves in a visual manner, allowing them to talk about their feelings as they react to an activity. It is very important to have a structured plan for each session. Resources are available that provide a wide range of games and activities that can be used to organize each session (see Resources).

Children usually will be resistant to joining a support group because they have no idea what to expect.

Children usually will be resistant to joining a support group because they have no idea what to expect. You and the child's parent(s) should try to convince him or her to attend just one session. Any resistance typically disappears after the first meeting because the children in the group have fun with each other.

Certain children will have difficulty participating in a hospital-based group program. Children who have severe behavior problems or learning disabilities may be unable to concentrate or to interact cooperatively with other children. Screening potential group participants is essential so that children with behavioral or other problems can be identified. If a child seems too troubled to participate in the proposed group, recommend an alternative source of help. Dealing with such a situation before a group cycle begins is much easier than having to consider removing a child from a group if problems develop. Obviously, any destructive, self-destructive, or suicidal statements or behaviors need to be taken with the utmost seriousness. As discussed in chapter 2, confidentiality cannot be maintained in such situations. It is your responsibility to consult with the parents and offer an appropriate referral if you are concerned that a child is at risk.

Any supportive group activity for children should have a complementary group for parents. Although offering a parent group along with a children's group is fairly labor-intensive, failing to do so is a wasted opportunity. Compared with a group facilitator, parents have a far greater impact on their child's ability to adjust and cope, so it is best to take advantage of that potential. The positive benefit of groups for children will be greatly enhanced by reaching out to parents who are struggling to deal with their child's reaction to illness.

A child's need or suitability for a particular group depends on whether the child himself is experiencing cancer, is the sibling of someone with cancer, or is the child or relative of an adult with cancer.

When the Person with Cancer Is a Child

Groups for Preschool-aged Children

The purpose of groups for preschool-aged children is to help them adjust to treatment events or procedures (e.g., lumbar punctures, bone marrow aspirations, surgery, catheter management, etc.).

Recommendations:

- Keep the groups small in size (i.e., six to eight children).
- Use two facilitators rather than one in order to manage behavior and pick up on meaningful verbalizations or behaviors. The point of using two facilitators is to combine the expertise of a person with group facilitation skills with that of someone skilled in engaging children in play activities (e.g., a social worker and a recreational therapist).
- Use therapeutic play, like drawing or working with clay, to foster expression through activities rather than verbalization.
- Keep abreast of the nuances of current treatment modalities. This includes knowing what children experience with treatment procedures, along with the expected side effects of drugs, radiation therapy, etc.
- Limit the group cycle to two to four sessions.
- Keep the groups goal-oriented, well structured, and directed. The structure should not be so rigid that it inhibits the natural spontaneity of children, however. Laughter, activity, and fun usually characterize groups for children. The facilitator(s) should have plans for each session and a general idea of the desired goals.

Groups for School-aged Children

Groups for school-aged children are generally activity-based and oriented around issues of coping and adaptation (e.g., adjustment to school, peer interaction).

Recommendations:

- Groups can be open-ended or closed, depending on the availability of staff and the population to be served. Closed groups, meaning those with a predetermined number of sessions, may work better because of the labor intensity of recruiting children. A cycle of six to eight sessions is reasonable in terms of commitment. Open-ended groups allow for sporadic attendance based on a child's changing health status but may not be practical in terms of the availability of facilitators or a child's commitments to school and other activities.

- As with preschool-aged children, use techniques that encourage school-aged children to express themselves through activities rather than verbalization. For example, ask children to draw a picture of how they feel about cancer or role play what a visit to the clinic is like for them. For support group facilitators needing information about activities that can be used in children's groups, see the Resources section at the end of this book under the heading "Children and Cancer."

- Again, use of two facilitators is optimal for planning and participating in activities and games and for helping to manage the children's behavior. A complementary group for parents should also be offered, if possible.

Groups for Adolescents

The purpose of groups for adolescents is to provide a safe place where they can freely express any developmentally-based concerns that have been heightened by disease. Adolescents may be able to verbalize their thoughts and feelings but still may need structured activities (e.g., watching educational videos, drawing, eating, etc.). Facilitators may be interested in the publication, *Quest: A Journal for the Teenager Whose Parent Has Cancer* (see "Children and Cancer" in the Resources section).

Recommendations:

- Because of adolescents' developmental struggles with authority, be aware of heightened sensitivity to issues of confidentiality. Be sure adolescents understand that self-destructive or suicidal behaviors are the exception to the rule of confidentiality. Reassure them that suicidal thoughts are not characteristic of a teenager's experience with cancer, but that if a member is suicidal, confidentiality cannot be maintained, and the teen's parent must be contacted.

- Be prepared to respond to issues such as sexuality, personal appearance, and resistance to authority, which are inherent in this developmental stage. Remember that you will be perceived as an authority figure and may have to make an extra effort to engage adolescents in the early stage of the group cycle.

- Be aware that medical decision-making will be more of a concern in this age group because of adolescents' tendency to test authority. Involving adolescents in their own medical care helps ensure compliance with and continuation of treatment. Groups for adolescents may offer an opportunity for teens to express their frustration that parents and medical staff seem to have total control over all medical decision-making.

- As with other groups for children, use of two facilitators is best. This format ensures continuity if occasionally one facilitator cannot be present, and it is helpful for sharing the intensity of emotionally charged issues. Teenagers are better able than younger children to express their fears about dying, and sharing in such conversations can be especially poignant for a facilitator. If you are new to facilitating adolescent groups, try not to worry that conversations about death will be frightening to the group. Although adolescents often seem unaware of their own mortality, it is a rare teenager with cancer who has not already thought about the possibility of dying. Facilitators should support the healthy denial that adolescents will exhibit in group situations unless the medical reality worsens for a group member, in which case the child can be dealt with individually.

Groups for Parents of Children with Cancer

Other than a child's death, probably nothing is more traumatic for parents than to learn that their child has a catastrophic or chronic, debilitating illness. The purpose of groups for parents of children with cancer is to enable parents to share their grief and fear with others who understand and to help them explore and anticipate how the childhood cancer experience will change their lives. Even though family life will never again be the same, people can be enormously helpful to each other in suggesting ways to accommodate the stresses of both the illness and its treatment.

The way in which these groups can be organized is widely variable. For instance, groups may be organized around a specific diagnosis, stage of illness, or treatment modality. All groups, however, are typically educational and supportive in nature.

Self-help groups for parents may spring up spontaneously in a community and be coordinated by the parents themselves, with the support of professional consultation. Other groups may be chapters of a national group such as Candlelighters.

Recommendations:

- Groups can be open-ended or closed. Open-ended groups may be advantageous because they are available if a crisis occurs or treatment needs to be intensified.
- Groups can be general in nature, or they can focus on specific educational themes such as setting limits, handling school-related issues, or dealing with discipline problems.
- Be aware that the level of individual functioning in the group may vary widely. Differences in parenting styles, marital relationships, and family stresses can translate to divergent points of views or approaches to problem solving among members. Because a pediatric cancer program may only have enough resources to offer one open-ended group, parents of children recently diagnosed with cancer may be associating with parents of children with more long-term illness. Although such exposure can be frightening to people who are newly confronted with cancer, it can also be reassuring to see that other parents cope if the worst happens and disease progresses.

- Use two facilitators if possible. These groups function well when a mental health professional and a medical health professional work together to respond to medical and psychosocial questions.

Sibling Groups

The purpose of sibling groups is to alleviate the sense of isolation and feelings of responsibility that siblings of children with cancer often experience. Children tend to assume responsibility for "bad things" happening, and siblings of children with cancer often worry that somehow they contributed to their brother's or sister's illness. This misconception can be dealt with easily in a group. The facilitator can say, "Sometimes kids worry that something they did or didn't do made their brother or sister get cancer. Doctors know that it's not possible for that to happen." It is better to offer that information up front rather than waiting for someone to have the courage to ask the question.

Siblings may become angry or resentful if their friends cannot be invited to play because, for instance, their brother's or sister's blood counts are precarious and infection is possible. At other times, a child's hospitalization may interfere with family attendance at a school play or other function involving the healthy siblings. A group can help siblings learn to cope with any feelings of anger, frustration, isolation, or guilt by offering a safe place to share these feelings with others and gain a different perspective.

Recommendation: The structural and facilitation concerns for sibling groups are the same as those for groups for children with cancer.

When the Person with Cancer Is an Adult

Groups for children who have a parent with cancer are becoming more common. The needs of these children are getting increased attention as we become aware of the profound impact parental cancer can have on developing children. If you are new to adult oncology and have had little experience with children, considering a children's group can be intimidating. Remember that children are resilient, have defenses of their own, and that their ability to cope is very much related to how their parents are dealing with the physical and psychological impact of cancer. Readers interested in generic information about children coping with a parent's cancer can obtain it from the American Cancer Society at www.cancer.org or by calling 1-800-ACS-2345.

Offer separate groups for children whose parents are undergoing treatment and children who are bereaved. These two groups of children have entirely different issues to address. Children whose parents are being treated have a different level of denial about the threat of parental death compared with children whose parents have already died. Bereaved children can talk about parental death more easily. If the parent of a child in your group dies, you should deal with this event by recognizing it and helping that child and the other group members express their fears, sorrow, anxiety, anger, guilt, and whatever other feelings may surface.

Groups for Children of Adults with Cancer

The purpose of these groups is to help children understand the nature of parental illness and its impact on the family, and to decrease their sense of isolation by meeting other children who are in the same situation. Although most children know others whose parents have gotten divorced, they are unlikely to know other children whose parent either has cancer or has died of it.

Recommendations:

- As with all groups for children, children of adults with cancer should be grouped according to age and developmental needs.

- Before deciding the appropriate group for a child, assess both the child and his or her parent(s). This screening will permit you to clarify the child's suitability for the group, assess the child's level of coping, determine the nature of the parent/child relationship, clarify both the parents' and the child's expectations, and deal with any resistance to participating in a group. As discussed earlier, most children are resistant to participating in a group. Suggest to parents that they encourage their child to attend at least one meeting. Usually, the fun that children have in these groups will overcome any resistance.

- Be aware that parental resistance to their child's inclusion in a group is often based on the natural tendency to protect their child. Parents usually fear that their child may learn about the possibility of the parent's death, and, depending on the time of the initial diagnosis, this fear can create tremendous anxiety. Parents who are struggling with a new diagnosis may need to move past this initial crisis before placing their child, or themselves, in a group. Parents need time to develop trust in the medical care delivery system and its staff before they can be expected to encourage their child to join a group. The screening process allows parents to meet the group facilitators and establishes a certain level of trust.

- Be alert to symptoms or behaviors that indicate the need for more in-depth and extensive evaluation and referral. Look for any exaggeration of the child's normal pattern of behavior, such as hyperactivity, exaggerated separation anxiety, depression, school problems, or child/parent behavior problems.
- Using two facilitators is optimal. One should have experience working with children (e.g., a pediatric social worker or nurse, an art or recreation therapist, or a teacher), and the other should have experience with group process.

The following activity-based resources are helpful in a group for children whose parents have cancer: *Kid's Night Out,* Fox Chase Cancer Center; *Life Isn't Always a Day at the Beach* by Pam Ganz and Tobi Scofield; *The Book of Psychotherapeutic Homework* by Lawrence Shapiro; and *Bear Essentials,* Missouri Baptist Medical Center. Videotape resources include "Talking About Your Cancer; A Parent's Guide to Helping Children Cope," Fox Chase Cancer Center; and "Kids Tell Kids What It's Like When a Parent Has Cancer," Cancervive/Pharmacia & Upjohn.

The following books are recommended for facilitators who want information about the needs of children with a sick parent: *How to Help Children Through a Parent's Serious Illness* by Kathleen McCue, MA, CCLS, and *When a Parent Has Cancer: A Guide to Caring For Your Children* by Wendy S. Harpham, MD. (See Resources under "Children and Cancer.")

Groups for Young Adults

A diagnosis of cancer can be devastating for a young adult, disrupting significant life decisions and plans, such as those concerning school, career, marriage, and parenting. These issues are most easily shared and discussed in a group with other people of the same age.

Young adults with cancer may have an underlying fear that their illness

The purpose of groups for parents of children with cancer is to enable parents to share their grief and fear with others who understand and to help them explore and anticipate how the childhood cancer experience will change their lives.

will force them into a more dependent relationship with their parents. A support group creates an environment in which young adults can regain some control over their lives and reassure themselves that they can still function in spite of their illness. The group also represents a safe place where young adults can explore the effect of cancer treatment on their body image and self-esteem.

The prevailing concerns of young adults with cancer include body image, sexuality, fertility, separation from parents, feelings of isolation from peers, as well as existential issues (e.g., the unfairness of life). A support group can provide a setting where these issues can be discussed. In a group of peers, young adults can also examine the dynamics of their relationship with their physicians and hospital. If treatment adherence is an issue for a young adult with cancer, a group can be a safe place to explore the implications of therapeutic decisions. In such situations, other young adults with cancer will often have more credibility than medical staff members, who will probably be exerting a fair amount of pressure to persuade young adults to accept treatment.

Depending on their age, social workers, nurses, or people with cancer who are facilitating a self-help group for young adults will be confronted with the fact that they and the members of the group are very much alike. Inexperienced facilitators will need to be aware of their own personal vulnerability and, as discussed in chapter 3, make a plan to deal with it. A group for young adults with uncertain futures is sure to bring the unfairness of life into sharp focus, and the experience can be stressful for a group leader.

Recommendations:

- Use a homogeneous format. The issues for young adults are very intense and present a natural bond around which members can organize themselves.
- Encourage existing members to aid in recruiting other young adults with cancer for the group. Members' commitment to the group process can be fairly powerful, motivating them to identify other young adults who can benefit from this method of support. In community hospitals or rural areas, the number of young adults with cancer may be insufficient to permit formation of a specialized group. In such areas, all members of a community, not just those from one institution, should be considered candidates for group membership. This is true for any diagnostic group or population with limited numbers (e.g., young people with testicular cancer or Hodgkin disease).
- Encourage members to maintain ongoing contact with one another between sessions and after completion of the group cycle.

Bereavement Groups

The purpose of bereavement groups is to ease the normal process of grieving and to prevent formation of abnormal or pathological grieving patterns. People who are experiencing their first significant loss have no way of knowing what to expect. Well-meaning friends may offer advice that is really not helpful (e.g., encouraging the bereaved person to prematurely dispose of the loved one's belongings or to start dating before psychological separation from the deceased has occurred). Bereaved people need to relive the illness experience repeatedly, and observing this process can be difficult for friends who are trying to help the bereaved "feel better." A support group can offer a much more realistic source of solace as members experience a gradual detachment from the loved ones they have lost. Accepting a significant loss requires time, and a group may be the only place where such painful and often conflicted feelings are tolerated. For professionals who, because of staffing constraints, are struggling to provide adequate services to families of deceased persons, recommending a bereavement group is reasonable. A support group can be a good alternative to individual counseling and is certainly better than no service at all.

A bereavement group can help people take the time they need to get through and normalize the feelings associated with the grieving process.

Bereavement support groups can take a number of different forms. Groups can be time-limited and closed (e.g., meeting for six to eight weeks, with no new members invited to join after the second session); ongoing, with meetings monthly, weekly, or bi-weekly; or a one-session program (e.g., coping with the holidays). Selection of a particular model is based on the need for the service in the community and the resources available to provide for it. Adults, children, and adolescents obviously belong in separate groups because their needs are unique to their own age groups.

Bereavement Groups for Adults

For most people, the death of a loved one causes intense sadness and emotional pain. If the death occurs after a long illness, it may also bring a sense of relief, which often makes people feel guilty. A bereavement group can help people take the time they need to get through and normalize the feelings associated with the grieving process.

The intensity of emotions in bereavement groups may be surprising and a bit overwhelming to inexperienced facilitators. It is one thing to talk to an individual who has just lost a loved one and quite another to be with a roomful of people who are expressing the pain of bereavement. Since the task of bereavement requires emotional catharsis and reliving of the illness experience in order to feel some relief, the facilitator may experience intense emotions. Facilitating a bereavement group can also stir up memories of personal losses. You should anticipate these problems and arrange ways to take care of your own sadness if it becomes problematic.

Common themes of bereavement group discussions include disposing of the loved one's possessions, visiting the grave, the expectations of family and friends, and loss of identity. In a bereavement group for parents who have lost a child, however, the issues discussed are different. Bereaved parents are concerned about reliving the illness experience, role changes, and, if there are surviving siblings, discipline and parenting problems. Losing a child is in no way similar to losing an adult. Bereaved parents will have little or no idea about what emotions and feelings are normal in this situation. Learning about the nature of such bereavement is of paramount importance for facilitators so they can educate parents and normalize these issues for them.

The structure and composition of bereavement groups can vary. Some groups include only people who have lost a spouse, while others are structured for people who have lost a parent, a child, or a friend. Although some people will feel comfortable in a mixed group, others may not. As discussed above, the needs of parents who have lost a child are unique. These individuals require specialized support and will not be comfortable among people who are grieving for an adult. If a support group for bereaved parents is not available in your community, an online group may be an alternative.

Recommendations:

- Do not try to speed up the grieving process. Rather, help to ensure that the process remains relatively unobstructed once it begins. Grieving will certainly continue after the group cycle ends, especially if the loss is relatively recent, but the group can provide insight and understanding of what the bereavement period entails.

- Educate bereaved parents about the impact of a child's death on any surviving siblings or other children in the family. Recommend reading materials, and share information about what is known about children's grieving process. Parents need to understand that manifestations of grief will emerge over a long period of time as surviving children move through different stages of development. An 18-year-old who is graduating from high school will miss the mother that he lost at age 10. Likewise, surviving siblings will experience a resurgence of their yearning for a lost brother or sister at each significant developmental milestone (e.g., the first date, graduation, marriage, etc.).

Refer people who are grieving because of a loved one's suicide to a group geared specifically to this population. The needs of people suffering a loss due to suicide are quite different from those of other bereaved people; their grief is greatly exacerbated by feelings of guilt and self-blame.

Bereavement Groups for Children

Bereavement groups for children are intended to help them develop an increased level of comfort in dealing with difficult feelings. Children's understanding of the permanency of death varies according to their age and level of maturity. Because of this variability, grieving children should be placed in separate, age-appropriate groups. In addition, children who have lost a sibling and those who have lost a parent belong in different groups. Children who are grieving the loss of a sibling should not at the same time be exposed to the possibility of losing a parent.[1]

Recommendations:

- Previously discussed guidelines for screening also apply to bereavement groups for children. Design meetings to be structured, with activities aimed at helping children get in touch with their feelings. Such activities might include games to describe the parent's or sibling's funeral or even a reenactment of it. Topics for discussions may include memories of the deceased parent or sibling, how to talk to friends and schoolmates about the death, or questions about cancer.

- Design groups to be time-limited. This format prevents children who are in the later phases of grief from having to revisit earlier phases when new members who are in the acute phase of grief join the group. Occasionally a child might wish or need to participate in a second series of meetings. If a child appears to be having significant conflict even after two series of meetings, consider referring him or her for individual help.

- If possible, establish parallel groups for parents that run concurrently. Such groups will help parents achieve some relief from their own feelings of grief so they can be more responsive to the needs of their child. These parallel groups are very important because the positive impact of a bereavement group for children will be diminished if parents are not able to help their child because of the intensity of their own grief.

- Schedule some meetings that include both the children and their surviving parents. If a parent is having difficulty getting the child to talk about a certain subject, design activities to help with that issue (e.g., jointly drawing a picture of the remaining family, making a clay mask of the deceased parent). During the grieving process, children and parents engage in a natural protectiveness of one another, and a joint activity may help to alter some of the very natural tendency to protect loved ones from pain.

Special Populations

Special populations (e.g., people who are socioeconomically disadvantaged, people of different cultural or ethnic groups, gay men and lesbians) have unique concerns that must be addressed by persons who are developing, facilitating, or encouraging support programs for these groups. However, the basic skills and issues identified and described in other sections of this book also apply to these special populations.

Self-awareness and sensitivity to ethnicity, gender, and sexual identity are essential when working with special populations. For example, effective leaders can think through their own ethnicity and their own perception of themselves; they have the ability to be sensitive to the fact that different ethnic or cultural groups have unique needs and concerns. Likewise, facilitators of groups for gay or lesbian people need to be reasonably secure about their own sexual identity and be comfortable discussing related issues.

Racial identity can have an impact on any therapeutic activity. This issue makes people profoundly uncomfortable, and hence it is avoided in many clinical situations and may become “the invisible elephant in the room.” A white social worker or nurse in an inner-city hospital should always acknowledge the racial difference when facilitating a support group comprising primarily African Americans. The same rule applies to an African American professional who is working with a group of white people. It is important to establish at the outset of any group that race is not a taboo subject, and that if group members are uncomfortable with the facilitator at any point in the process, it is OK to bring it up.

Self-awareness and sensitivity to ethnicity, gender, and sexual identity are essential components of effectiveness when working with special populations.

A white social worker facilitating a group of African Americans might say something like, "It's obvious that I am a different color than the rest of you in this room. Is anyone concerned that I won't be able to understand where you're coming from?" Although people may or may not be able to respond honestly, the mere fact that you have asked the question means that you are aware of the potential for problems and are willing to deal with them.

People of different cultures and backgrounds define and cope with problems differently, and these variations will affect the way they seek and accept help. Depending on their sensitivity to the cultural values and traditions of others, facilitators may be viewed either as people appropriate and safe to call on for help or as intruders. It would be very unfortunate to have a group fail because the members doubt the credibility of the leader. For this reason, the facilitator should introduce the topic of diversity because it is unlikely to arise spontaneously from group members.

Setting up the Group

When setting up a group for special populations, consultation with a professional who is indigenous to that population will help ensure the success of the group. Regardless of the target population, several guidelines should be considered.

Site selection. As discussed in chapter 2, people generally have little interest in returning to the hospital for a support group unless the facility is located close to their homes. If possible, meetings should be held in the community, perhaps in local churches, community health centers, or other central meeting areas. The best location is one that is meaningful to the group members. An organization that provides space should be encouraged to co-sponsor the group.

Group selection. Because identifying and recruiting participants for a particular group may be difficult, it is useful to ascertain their needs, cultural values, and beliefs about illness. Attitudes about public disclosure of an illness outside the family and participation in a group of mixed gender or age should also be considered. Organizing a group based on the site of cancer, gender, and background may be appropriate (e.g., a group for African American women with breast cancer).

Community co-facilitator. If a facilitator has expertise in either group support or coping with the disease but does not have the same background as the group participants, a co-facilitator from the participants' community can be helpful in establishing rapport, validating the facilitator as an interested and trustworthy leader, and bridging any language or cultural gaps.

In addition, members of a specialized group might be more comfortable talking with one of their own who they feel will better understand and respect them. A facilitator who lives in the same community as group members has a general understanding of their living conditions and social problems, and how these factors may affect group participation. For example, a group member who lives in a small space with several other family members may not have either the privacy or opportunity to deal with emotional issues. Participants of some cultures may be considered self-centered by their family members if they are found crying or are fearful of treatment. Participants might feel embarrassed or humiliated to reveal such things to an outsider but may feel comfortable enough to discuss it with a co-facilitator from their own community.

If the preferred language of the group is different from that of the facilitator, a bilingual co-facilitator from the community should be sought. The qualifications of the bilingual co-facilitator are less important than his or her desire to assist with the group, as long as confidentiality, trust, sensitivity, and respect are maintained. It is more important to have a bilingual co-facilitator who may have no experience with groups or even cancer than to have no bilingual assistance.

Marketing the Group

In addition to the general marketing suggestions discussed in chapter 2, marketing for special populations should include use of local community newspapers that are targeted to a particular cultural or religious group. Holding group meetings in community churches or other trusted facilities adds considerable legitimacy.

Concrete Needs

As discussed in chapter 2, the need for concrete services such as babysitting and transportation may be particularly important to members of socioeconomically disadvantaged populations. The lives of many poor people can be incredibly complicated by basic survival issues. Therefore, facilitators of any group program that is offered to such populations should be sensitive to the many constraints that exist for some members.

Starting the Group

As in any group support program, establishing trust is the most important task to accomplish at the beginning of the group cycle. Having a community co-facilitator, meeting concrete needs, having a positive initial social interaction, and meeting in a community facility all contribute to the establishment of trust. It is also important to recognize that participants may:

- lack a basic understanding of the purpose of the group or its process
- resist talking about cancer and/or themselves and their feelings
- be unwilling to ask questions or expose their lack of understanding
- have a different sense of time (e.g., they may not place importance on being at meetings at a specified starting time)
- have values that conflict with those of the group facilitator (e.g., they may resist expressing their feelings, crying in front of non-family members, or offering mutual support)
- have problems with verbal fluency

Each of these issues needs to be addressed in a very open and straightforward manner consistent with the culture or ethnicity of the group.

Ethnic/Cultural Groups

The previous guidelines for special populations also apply to ethnic and cultural groups. In addition, groups for people of different cultural and ethnic backgrounds often have several issues that are unique to them. Following are some recommendations for working with people from diverse cultural groups.

Recommendations:

- Assess the degree of acculturation of the group members and their families to the health care delivery system and to the majority culture.
- Identify the person who makes the decisions for the family regarding health care matters.
- Assess whether or not group participants and their family members see health care professionals as authority figures and are therefore uncomfortable expressing their own opinions. For example, in some cultures (e.g., Asian American) it may be considered impolite to ask questions of health care providers, especially physicians. Persons from certain backgrounds may have a tendency to withhold questions.
- Realize that asking, “Do you have any questions?” may not elicit questions from group members. Try to provide specific information regarding diet requirements, treatment regimens, physical issues, and use of resources. Speak with professional knowledge but without an authoritarian demeanor.
- Acknowledge that some physicians have a tendency to withhold information regarding a person’s illness. Studies have shown that such reticence is even more common when the physician and patient are members of different socioeconomic groups.[2]
- Groups can help members take an active role in eliciting more information from their physicians.
- Identify feelings and attitudes about having cancer, as you would do with any group of people.

- State clearly that members have the option to consult another physician for a second opinion. In some cultures, such a consultation would be considered offensive to the primary physician. Assure participants that a second opinion is valued, and encourage them to seek one as appropriate.

- Identify each member's perception of and attitude toward receiving help. Some people may feel embarrassed or ashamed about receiving help from someone outside the immediate family or may be uncomfortable with a provider who is much younger or older.

- Always verify that members whose primary language differs from that of the group understand what is being said. Nodding, smiling, or saying "yes" could mean that they understand or that they are just trying to be polite. Let them know that they can say "no." Be aware that an experienced interpreter may have a role, as discussed earlier in this chapter.

- Do not assume resistance or lack of cooperation if a member avoids eye contact. It is very common in some cultures to avoid direct eye contact.

- Be aware that group members may be suppressing pain or other emotions because of a cultural norm. It is common in some cultures for people to withhold feelings, and/or it may be a traditional practice to put other people's needs before one's own. These members may be helped by a group experience that encourages self-expression.

- Be sensitive about religious beliefs. Knowing members' religions may lead to a better understanding of how they deal with events such as illness and death.

- Be aware that some cultures and religions believe in folk or nontraditional medicine. Among the Chinese, for instance, herbal treatments are very common. You might want to inquire, "What other things are people doing to fight their cancer?" as an automatic part of the group process, rather than assuming that members will tell you spontaneously. Understand and respect each member's right to follow any nontraditional practices, preferably not as an alternative to standard medical care but as an adjunct to it.

- When setting up and planning for a group that you know will include people of different cultures, investigate cultural norms. It will be helpful to know in advance, for example, that direct physical contact may not be a common or acceptable practice, especially between the facilitator and participants of the opposite sex or the facilitator and family members.
- Speak carefully, and use nontechnical language as much as possible.

Groups for Specific Cancer Sites

Guidelines for facilitating a site-specific group are basically the same as those previously discussed but can be modified to suit the group's needs. Regardless of the cancer site, leaders for site-specific groups have the following obligations:

- Be informed and up-to-date about the specific cancer. Because no one can be an expert in everything, cultivate a group of speakers who can address certain topics. For example, a surgeon could be invited to explain breast reconstruction to a breast cancer group, if members are interested.
- Be attentive to sensitive gender issues that can arise in same-sex groups (e.g., body image concerns for women who have had a mastectomy or erectile dysfunction for men with prostate cancer). These issues have to be handled with great care and sensitivity. Obviously, you will need to be aware of possible barriers to communication. For instance, men with prostate cancer may be unwilling to discuss intimacy problems with a young female facilitator; likewise, the facilitator may be uncomfortable with an open discussion of sexual issues. You should acknowledge to members that awkward and sensitive issues do exist. In some situations, engaging a speaker to address a topic medically, then following up with a discussion of more emotionally-laden content may be advisable.
- Sometimes you will feel uncomfortable in the role of facilitator because no one person can mirror the identical characteristics of everyone in a particular support group. You do not, however, need to apologize for who you are. The differences between you and the group members will be less of a concern as people get to know each other. You can learn a

great deal by facilitating a site-specific support group in terms of the issues and concerns of its members.

- Be aware of problems that may occur if the group includes individuals with different stages of disease. Combining people who have localized cancer and those with metastatic disease can create an urge to flee among those whose cancer is in the early stages. Because facilitators may not be in a position to control group membership (e.g., an open group in a new market area), be prepared for this common reaction of persons in the early stages of disease. Of course, the opposite reaction can occur, with persons with early-stage cancer feeling relieved and better off compared with other members.

- Group cohesion may be difficult to establish if members have different stages of disease because they obviously will not share the same concerns. Handle such groups with special care. If the group includes members who are in different stages of illness, acknowledge the differences, and encourage members to discuss how they individually keep themselves separate from the experiences of other group members. Questions such as, "Is it scary for you to hear about his recurrence?" give the early-stage person an opportunity to react, along with an acknowledgment that the person with recurrent disease may not want to take the risk of upsetting others. If the issue is never discussed and members remain uncertain about negotiating that terrain themselves, they may simply stop attending. In such instances, a professional with training in group facilitation may be better able to handle a group with mixed stages than a non-professional facilitator.

Advantages

Several advantages are unique to site-specific groups.

- As discussed in chapter 2, cohesion develops quickly in any homogeneous group. In site-specific groups, however, even more cohesion is possible, because everyone has cancer at the same site. Having the same cancer site makes it easier for members to identify with each other's experiences, medical treatment, and emotional reactions.

- Sharing the same site-specific problems can also help group members bond and develop immediate empathy, since they see each other as being in the same boat.

Sharing the same site-specific problems can also help group members bond and develop immediate empathy.

- Members have similar interests in the progress of any site-specific research and can share specific symptom management and coping skills with each other.
- It is easy to identify and recruit potential members. Men with prostate cancer can be recruited through hospitals, clinics, or their physicians, for example. A group for women with breast cancer can recruit new members through Reach to Recovery,® a Society sponsored one-to-one support and rehabilitation program specifically designed for women with breast cancer.

Disadvantages

Several disadvantages are unique to site-specific groups.

- Sometimes site-specific issues can be given too much emphasis. Focusing on the same issues again and again can make members turn inward and forget the rest of the world at a time when they could be moving on.
- When all members have the same cancer site, it is easy for both the facilitator and the group to lose sight of issues that apply to all cancer survivors, such as employment concerns, insurance problems, pain, isolation, and family matters.
- Identification is beneficial up to a certain point, but site-specific groups may also cause anxiety. For example, if a healthy member sees another member with the same cancer having serious problems, the healthy member may become anxious about having to face that same problem someday. As discussed earlier, it is important to establish a balance, reassuring the healthy member without downplaying the fears of the sick member.
- In some areas, the number of people with the same diagnosis may not be sufficient to support a site-specific group. A generic group would be better than no group at all.

Recruitment Strategies

The generic recruitment strategies discussed in chapter 3 can be altered as appropriate for site-specific groups, making certain changes based on the site, type of community, etc.

Site-specific groups require fewer contacts to recruit a core group, may use participants to recruit other group members, and may be more participant-driven than other groups.

Three Specific Cancers

Following is a discussion applicable to three site-specific groups, along with comments about two other groups of people who share certain characteristics. The site-specific groups are for people with Hodgkin disease, breast cancer, and prostate cancer. The groups for people with common characteristics are family caregivers and people who are at high risk for developing cancer.

Although Hodgkin disease occurs with high frequency among both young adults (aged 21 to 40 years) and older adults (aged 50 to 60 years), breast cancer and prostate cancer occur more frequently in older populations. Regardless of which disease they have, older people share certain issues in common. For example, they may be concerned about retirement, change in residence, sexual problems, co-morbidity issues (heart disease, diabetes, etc.) for themselves or their spouses, or fear of loss of their spouses. It is important to be sensitive to the life-transition and developmental issues of people of all ages. Although cancer is the common issue specific to all of these groups, note that age is a significant variable in the psycho-dynamic issues with which these people are dealing.

Hodgkin disease

Facilitators of groups for people with Hodgkin disease should be aware of certain issues. Although the severity of disease may vary among the group members, Hodgkin disease is highly curable. Members may appear to be optimistic about the outcome but nevertheless can struggle with fear of recurrence and death.

People with Hodgkin disease have age-specific issues. Young people are often concerned about:

- school and career interruptions
- infertility, childbearing, and the question of sperm-banking
- vulnerability of intimate relationships
- renewed dependence on parents
- late complications such as recurrence, pulmonary and cardiac changes, and early detection of related diseases

Middle-aged people may be concerned about:

- role changes as their children leave home to go to college, start careers, or get married
- planning for their own retirement
- caring for elderly parents
- planning for their own care if they are ill

Older people may be worried about:

- relocating due to retirement
- leaving family and friends
- age-related health problems they or their spouse may be facing
- fear of a spouse dying

A factor that complicates a group for people with Hodgkin disease is the good prognosis often associated with the illness. Because of the expectations for a good outcome, people with Hodgkin disease may feel they do not have the right to react to the fact that it is still a catastrophic disease; many years may pass before they feel safe. Conversely, people with Hodgkin disease and their families may feel very bitter and cheated if the disease cannot be cured. A support group can be a source of comfort to people who are struggling with these issues.

Breast cancer

Facilitators of a group for people with breast cancer also should be aware of specific issues.

- Although breast cancer occurs more frequently among older women, the range of ages in a group can be wide. Many problems discussed in the group may be age-related. For example, an older woman might worry about "passing the disease on" to her married daughter, while a younger woman might worry about how a mastectomy will affect her sexuality. As always, it is important to balance everyone's need for support and information. As previously discussed, avoid mixing people with early-stage or localized cancer and those with metastatic disease, whenever possible.

- The wide range of treatment options for all stages of breast cancer may be overwhelming for some women. As they compare their own medical therapies with those of other women, hear about a new drug on the news, or read about possible dietary links to breast cancer, a woman may begin to question whether she is doing the right thing for herself. Facilitators need to be well informed and as up-to-date as possible about all treatment options so they can participate without imposing personal biases. They need to know when to refer members to their physicians for further information.

- Women may have heard about research demonstrating that participation in a support group is likely to extend their lives. Even though there is no definitive proof that this is true, you should be sensitive to the fact that participants will want it to be true. The emphasis of meetings should be on the benefits of group support in coping with the physical and emotional impact of cancer. If the group helps women feel more in control, less anxious, and better able to deal with the uncertainty of the future, that is obviously a very positive outcome. The quality of people's lives is much improved by the opportunity to advocate for themselves and to reach out to others who are contending with the problems of cancer diagnosis and treatment.

- Group members may have partners other than husbands. Be aware that some people might be offended if other members are not married to their partners or have female partners. Similarly, women in same-sex relationships may have difficulty relating to the concerns of male-female couples. Such issues should be sorted out before the group cycle begins so that all participants will feel accepted and welcome. Cancer itself has the potential to make women feel stigmatized; they should not have to feel penalized for their lifestyle also. The needs of all members of a group should be balanced. Regardless of the gender or relationship of their partners, members must feel that their concerns about their loved ones are understood and respected. Having separate groups for male and female partners might be useful, if feasible.

- Treatment-related problems that are site-specific (e.g., lymphedema, prostheses, reconstruction, back/arm care) are likely to affect someone in the group. Other concerns attributable to breast cancer therapy include body image changes, sexual problems, and hair loss. In addition, because mammography is ongoing, many women face test anxiety on a regular basis. Be aware of such potential problems and have a plan for helping members deal with them. Also consider how inclusion of someone with those problems might affect other members of the group. By anticipating these possible difficulties, facilitators can be prepared to offer information or suggestions.

- An important concern for women with breast cancer is the associated risk for family members. You should anticipate expressions of fear or anger and a lack of knowledge. Educate members about the risk of breast cancer for their daughters and sisters, and emphasize the importance of regular mammography, clinical breast exams, and breast self-exams for these relatives. Limited knowledge about the so-called "breast cancer genes" is a source of confusion for women with a family history of breast cancer. Although it has been established that some women have a genetic predisposition to development of breast cancer, only a small percentage of women with breast cancer carry these genetic mutations. It is important to clarify this for women so they do not give their daughters incorrect information.

- Younger women may have questions about fertility and pregnancy. It is important to acknowledge any concerns, feelings, or fears that members have and ascertain if they have discussed these issues fully with their physicians.

Prostate cancer

When facilitating a group for men with prostate cancer, be aware of the following issues:

- Although prostate cancer strikes primarily older men (age 50 and older), there can be a wide range of ages in a support group. Remember that each age group has its own developmental concerns. For example, older men with prostate cancer may be concerned with urinary symptoms and pain, while younger men may be struggling with anger over the untimeliness of their illness and changes in their ability to function sexually.
- Whenever possible, avoid mixing men who have early-stage or localized cancer and those with metastatic disease.
- Be aware and well informed about the variety of treatment options for all stages of prostate cancer. Like women with breast cancer, men with prostate cancer will compare their medical therapies with each other and might question whether what they are doing for themselves is right. Stay as up-to-date as possible about treatment options, and refer a member to his physician for further information, if necessary. Also, be aware that sexual rehabilitation is available for men with prostate cancer. It will be important to identify sexual rehabilitation counselors who have experience with men with prostate cancer.
- Some members are likely to experience site-specific problems as an aftermath of treatment (e.g., erectile dysfunction, incontinence). In addition, because prostate-specific antigen (PSA) testing is ongoing, many men face test anxiety on a regular basis.

There are a variety of models for prostate cancer support and self-help groups. Some are locally based and may or may not be sponsored by a physician or a clinic. Self-help groups may be coordinated by a member or led by a professional. Both Man to Man® and Us Too are examples of such groups for men with prostate cancer. Both meet monthly, focus on education and support, and include wives or partners.

Groups for Family Caregivers

About half of the oncology population faces progressive illness and/or death. Therefore, the issues related to being a caregiver are significant. Because people with cancer no longer spend prolonged periods of time in hospitals, it is becoming increasingly less likely that death will occur in an institutional setting. With the exception of hospice programs, the circumstances surrounding the deaths of people with cancer will vary tremendously. This obviously has implications for family members who are providing care or anyone else who is close to the person with cancer and assumes the responsibility of caregiver.

In addition to the emotional stress associated with witnessing a loved one dying, the physical demands on caregivers of people with advanced cancer can be overwhelming. Family caregivers often are expected to perform procedures that once were performed only by nurses; for an exhausted relative, such tasks can be quite frightening. A group for caregivers can provide enormous relief as they share their anxiety and sadness about the impending loss.

Obviously, individuals dealing with the cancer experience have relationship histories, some of which are good and others that are associated with preexisting conflicts. The caregiving situation can provide a setting in which all of that history can be revisited. For example, if a member of a couple with a troubled marriage becomes gravely ill, it is unlikely that the state of the marriage will improve or that the spouse will feel successful in the caregiving role. People who are put into the position of caregiver can feel enormously guilty and resentful. Caregivers can also feel angry about the impact that cancer has on family life and may have no outlet for those feelings.

People with cancer who are not actively dying may want to participate in the group, but this is not usually recommended. Caregivers should be able to freely express their feelings of anger or frustration, and the person for whom they are caring may not be in touch with the caregiver’s stress. Separate groups for persons with end-stage illness and their caregivers may enable both to better appreciate each other’s needs.

Regardless of a family’s history, feelings of anticipatory grief will probably occur and can complicate the caregiving relationship. Anticipatory grief occurs before the actual death. Talking about the family member in the

In addition to the emotional stress associated with witnessing a loved one dying, the physical demands on caregivers of people with advanced cancer can be overwhelming.

past tense is one sign of anticipatory grief. In fact, people with late-stage illness may be far more ready for their deaths than their family members and friends are. Actually experiencing the disease process for a very long period of time can sometimes make the person more ready for death and an end to suffering than the family can appreciate. It is possible that the person with cancer and his or her family will be very out of touch with each another. All of these issues can be addressed in a group. It is likely that most members will experience these complex feelings to some degree.

Often the most challenging issue for the facilitator is deciding when to offer a group for caregivers. Depending on their perception of how safe it is to leave the person with cancer, caregivers may be extremely reluctant to participate. Their participation may also depend on the availability of respite programs specifically designed to give caregivers some relief from the day-to-day stress of caretaking. Support groups for caregivers often take the form of education about physical caretaking, procedures, pain assessment, and managing side effects, with equal emphasis on the emotional needs of the caregiver.

For some people, attending such a group will be out of the question if they cannot identify someone that they trust to stay with their loved one. In addition, family members may be unable to appreciate the degree of their own stress or unwilling to give themselves permission to express their own needs. Telephone groups are a wonderful alternative in such situations, even though a certain degree of relief occurs simply by leaving the home setting. However caregiver groups are offered, they can be a real lifeline for families or friends of dying persons. When death does occur, survivors will be left with their memories of how they behaved and managed during both the illness and the eventual loss. If they believe that they fulfilled their obligations to their loved one, it will be much easier to resolve the loss and to go on with their lives. A support group for caregivers can help people plan what they will need for themselves and help them avoid self-blame when their loved one is gone. Participation in a support group can make the difference between resolution and self-blame, and facilitating such groups is well worth the effort for those who are invested in helping people go on with their lives.

Groups for People with a Genetic Risk of Cancer

Only recently has it become possible to identify people who have a higher risk than the average population for cancer. Risk assessment programs are available in many medical settings, and people with a family history of breast, ovarian, prostate, and colon cancers are now able to have genetic testing to ascertain whether they have a genetic predisposition. Although this medical development is very exciting, it has profound implications for the men and women who carry such genes.

From a psychosocial point of view, this field is in its infancy. Definitive information about people with a genetic predisposition to cancer is minimal. For instance, the following questions come to mind about the psychosocial needs of women with a higher risk for breast or ovarian cancer:

- How does carrying a gene make them different from women who are at higher risk because of their family history?
- In what ways are they different from people at risk for other catastrophic diseases like Huntington disease?
- How is the marital and sexual relationship affected by high-risk status?
- When should daughters of these women be told about their higher risk?
- What therapeutic interventions are helpful to this population?
- Should radical interventions such as prophylactic mastectomy or oophorectomy (removal of the ovaries) be encouraged?

These are only a few of the questions about the needs of this special population. Obviously, more will be known as research studies are implemented. In the meantime, social workers, genetic counselors, and nurses who work with members of this population will need to offer services to them.

Support group facilitators have the opportunity to acquire important data about the needs of people with a genetic risk for cancer. As is true about any cancer population, it is important to learn as much as possible about the issues associated with this group of people before offering them services. Genetics is a complex field, and facilitators should have a basic knowledge about genetic issues and counseling so that they are in the best position to correct any misconceptions among group members. They should also be knowledgeable about health insurance and job discrimination issues for people who have tested positive: will they be denied benefits or job opportunities because their futures may be uncertain? Although people in this population may not have experienced problems in these areas, they will certainly worry about the future. People with a genetic predisposition may be inclined to keep their test results secret from others, leading to the possibility of increased anxiety and stress. Obviously, concerns about how high-risk status will affect their children will also be pervasive.

Clearly, we have much to learn about how best to help such people and how support groups can be designed to respond to their specific needs. Facilitators should appreciate how critical it is to acquire accurate information about this population and preserve as much of their experience as possible in written form.

References

1. Christ GH. *Healing Children's Grief.* New York, NY: Oxford University Press; 2000.

2. Merrill J, Laux L, Thornby J. Troublesome aspects of the patient-physician relationship: a study of human factors. *Southern Med J.* 1987;80:1211-1215.

5

Telephone and Online Support Groups

Yvette Colón, MSW, ACSW

Telephone Support Groups

Introduction

As we have seen throughout this book, self-help or support groups can help guide people with cancer, their loved ones, or the bereaved through the process of coping and normalization. The emotional support and social networks provided by support groups can be effective alternatives to reliance on family, friends, or the health care team.

Support groups are usually held in person at a designated place and time. Sometimes, however, people who could benefit from a traditional support group are unable to attend. These may include people who are home-bound or debilitated by treatment, caregivers who have competing demands on their time, or people who live in rural areas with few psychosocial support services. In these situations, the telephone can be a practical option for conducting support groups. Telephone support groups can be cost efficient and highly effective. Counseling through the telephone maintains privacy and can serve to diminish social isolation, anxiety, and depression. A telephone support group program also can include more participants of varied diagnoses, ages, and ethnic backgrounds.

Recruitment, Screening, and Assessment

As in a traditional support group, a facilitator of a telephone group assesses the number of clients who could benefit from emotional support and socialization and evaluates a client's interest in and need for this service. Clients who are isolated or unable to travel but who can speak about their emotional concerns can be considered for membership. Those who cannot verbalize their concerns, are not able or willing to discuss emotional issues, or who want only to socialize should be excluded. The facilitator must assess an individual's motivation to participate in a telephone support group and gather information about his or her functional status and any existing social supports. Additionally, it is important to explain the focus of the group and how the group works. Facilitators can reassure and motivate clients by providing simple, direct answers to their questions.

Some potential group members may exclude themselves from the group before it even starts because they are too ill to participate, are not ready to explore their emotional concerns, or are uncomfortable using the telephone for group sessions.

Format of Group

Before any potential participants are contacted, the facilitator must decide whether the group will meet by telephone every week, every other week, or once a month. If the group meets weekly, it can last for one hour. If it meets every other week or monthly, the facilitator can decide whether 90-minute sessions will be sufficient. The focus of the group can be educational and/or supportive in nature. The facilitator must inform the group members of the intended structure and focus of the sessions, whether the group will be open-ended, and whether each session will have a specific agenda.

Practical Matters

The size of the group is important. Groups with too many members are difficult to manage and may not permit all members sufficient time to address and explore their concerns. Members of groups that are too small may feel unsupported or unsatisfied. Members will sometimes miss sessions because of hospitalization, treatment schedules, or distressing side effects of treatment. An average of 12 members in any group will ensure an adequate number of participants for each session and still allow enough time for in-depth discussion.

The cost of a group will vary depending on the service provided. A facilitator can conduct small groups by originating calls to participants using the conference call feature that is available on many business telephones. This type of meeting can be conducted at minimal cost.

Before starting any group, the facilitator must have a conversation with the operator to explain what the group is about, to stress confidentiality and noninvolvement, and to answer the operator's questions.

Because the facilitator is placing the call, participants do not incur any costs.

Telephone companies offer different services to originate calls to participants. Charges vary per person depending on the level of service requested. Participants do not incur the cost of the phone call. Another service is available in which participants make the initial call and are then connected with each other internally through the telephone company. With this method, participants incur the cost of the phone call.

When meetings are conducted as conference calls using an outside telephone company, the operator has an important role because he or she will be the first person to interact with each group member as the session commences. Some groups may want to have consistent, ongoing contact with the same operator. In any case, before starting any group, the facilitator must have a conversation with the operator to explain what the group is about, to stress confidentiality and noninvolvement, and to answer the operator's questions. Group members should be aware that the operator will not participate in the group but will need to monitor a session occasionally to make sure there are no technical problems.

Again, depending on the level of service used, an operator can put confused, disoriented, or disruptive group members on listen-only mode. Although the facilitator can still hear the disruptive group member as well as the regular group conversation, the other group members cannot hear the disruptive group member. The operator also can be notified automatically if someone is disconnected, and the facilitator can contact the operator at any time during the session simply by pressing "0" on his or her touch-tone telephone.

The facilitator may wish to provide written instructions and guidelines to participants before the first group session or when a new member joins the group. With permission from the group members, the facilitator may distribute a list of their addresses and telephone numbers and encourage them to socialize by telephone between sessions. The facilitator can help participants differentiate between formal, structured, scheduled calls and informal, unscheduled, intermittent calls. Some participants may need help distinguishing the difference between group sessions and general group-related conversations that take place outside of the scheduled time. Participants of telephone support groups often develop personal relationships with each other and may wish to have contact outside of the group. In this case, the facilitator can request that group business be discussed only in the group sessions and remind participants to maintain the confidentiality of the others.

If socializing and networking between sessions are encouraged, the facilitator can send updated lists of group members, newsletters, articles, and other written information of interest that members may want to share with each other.

Starting the Session

Before the start of a group session, either the facilitator or an outside operator calls each member using the conference call feature. After all participating members have been reached, the facilitator connects to the call, and the session begins. Each member can be addressed by the facilitator individually and given an opportunity to speak, or the meeting can take the form of an open discussion of issues of concern to all participants. The facilitator can guide members until a group process and structure develops that is mutually beneficial. The facilitator can help keep members focused on their emotional concerns.

Issues for Facilitators

Telephone support groups provide many benefits. Group members can transcend physical or geographical limitations, receive support to which they otherwise would not have access, and have the opportunity to connect with others in similar circumstances.

Use of the telephone can create a more comfortable atmosphere for clients because they are in familiar surroundings during sessions rather than the structured environment of a hospital meeting room or a facilitator's office. Participation in telephone sessions can remain consistent for members. Clients who feel well enough can participate in sessions whether they are at home, in the hospital, at a family member's home, in a nursing home, or traveling. For example, if a group member can no longer remain at home, he or she can count on the continuity of group sessions. As long as group members have access to a telephone, they can continue to participate fully.

The relative anonymity afforded by participation in a telephone support group is a source of comfort to some people. This structure allows them to achieve closeness while maintaining a safe distance. Some people in face-to-face meetings may feel too inhibited to talk with a group of virtual strangers during the early phases of the group process. Others may feel self-conscious if their physical appearance has been altered by surgery, or if they have lost a lot of weight or are weakened by the side effects of treatment. Without this social inhibition, group members feel more comfortable sharing their problems and worries. As a result, increased self-disclosure and bonding will occur early in the group process, leading to deeper and more direct discussions.

The level of intimacy will vary according to the length of the group cycle. People who know that they will be able to participate in the telephone group together for a longer period of time can explore their emotional concerns to a greater degree instead of feeling compelled to remain focused on practical and concrete issues.

Clinical Issues

In telephone support groups, the facilitator and group members do not have the benefit of visual cues that are present in a face-to-face group. This can be problematic, because the facilitator must listen in a different way. Instead of relying on visual cues, the facilitator must pay close attention to language, tone, and inflection. He or she must also pay attention to the ways in which group members speak and relate to one another when they are well and coping adequately compared to when they are ill or under stress. For example, an astute facilitator will hear the pain in the voice of a member who has trouble with pain management but says he is feeling fine. The facilitator may then draw that person out a little more, give him some extra support, and provide information about available resources. Facilitators of telephone groups may need to take an

Participants in a telephone support group primarily discuss the emotional impact of their own or their loved one's illness.

active, more direct role in the group to compensate for the absence of eye contact and body language.

Participants in a telephone support group primarily discuss the emotional impact of their own or their loved one's illness. Participants who are ill may discuss the problems of isolation and intimacy, the changes in their relationships with family and friends, and the alteration of their self-image. Mortality, health care decision making, and survival issues will be spoken of regularly. Participants who are family members will discuss their coping strategies, approaches to problem solving, and the often overwhelming demands of caregiving. People who are bereaved will share their profound pain and grief and the experiences of putting their lives back together after the loss of a significant person in their lives. Many of them will explore issues of helplessness, regaining control, and loneliness. They will also share strategies for improving communication with the health care team, ways to advocate for themselves and their loved ones, and methods for finding the resources they need. They will also share their courage and creativity with each other and encourage others to persevere.

A facilitator of a telephone group promotes group cohesion, provides structure and information, and encourages helpful and supportive relationships among the members.

Group Management Issues

Just as with face-to-face groups, the death of a participant in a telephone group is a difficult experience for both the facilitator and the other members. Because of physical limitations or geographical distance, members are very often unable to attend a funeral or memorial service and therefore cannot participate in any social rituals that will help them come to terms with the death and achieve closure. Sometimes the facilitator is the person who informs the group of a member's death. Group members may not be able to tolerate an entire session devoted to discussing the death. The facilitator can support the members in discussing the death over the course of several sessions and encourage them to share any stories or history of the deceased member's participation in the group.

In many cases, the facilitator and members of the group do not meet face-to-face before the start of the group. Because of this, members may idealize the facilitator or project unrealistic demands. Anger and frustration can be taken out on the facilitator, who is seen as a representative of the medical system. (Obviously, this can also happen in face-to-face groups.) Similarly, the facilitator's idealization or preconception of the clients also can be problematic. Facilitators who have only a mental image of the group members may visualize participants as being healthier or functioning at a higher level than they really are.

Assertive, verbal group members may want to take on the role of co-facilitator or begin to dominate the discussions. In such cases, the facilitator must redirect the conversation to the topic being discussed rather than singling out one or two members. It may become necessary to have a private discussion with the dominant group member (who is often influential) to determine how that member can continue to help and support the group without taking over and excluding the less verbal participants.

Meetings of face-to-face groups are held in closed meeting rooms that offer privacy and safety. During telephone support group meetings, however, family members or other persons may be present or nearby during the session. These bystanders may be interested in a particular problem, or they may want to share information and therefore pick up the telephone extension to talk with the group or the facilitator. As with any other interruption or crisis (e.g., a hostile or disruptive group member), the facilitator must stop the group discussion immediately, state the purpose of the group, review the importance of confidentiality, and politely but firmly request that the non-member leave the group immediately. Group members need to feel safe and believe that the facilitator will protect the privacy and integrity of the group.

In summary, telephone support groups are a very viable and creative alternative to traditional support groups. They offer an opportunity to reach out to people who, through no fault of their own, would otherwise be excluded from psychosocial support services. They also are attractive to sponsors as an innovative and cost-efficient model of service delivery.

It is recommended that both professionals and non-professionals who wish to facilitate a telephone support group first gain experience with face-to-face groups. Telephone groups obviously lack any visual cues regarding the dynamics of participant interaction. Therefore, facilitators need to come to the experience feeling confident about their management skills, their sensitivity to the nuances of spoken and unspoken communication, and their ability to handle difficult behaviors.

For facilitators who have acquired the basic skills of managing a support or self-help group, telephone support groups can be an exciting and creative way to offer people with cancer and their families the benefits of a support network.

Online Support Groups

Introduction

With the advent of online forums for virtually every medical concern, more and more people with cancer and their caregivers are turning to the Internet for support and information. The demand for online services is high, and the number of participants in online groups is increasing. Because of this technological explosion, attitudes are changing about ways in which people dealing with cancer can get information and support.

Many people who could benefit from a traditional support group would prefer to participate in an online forum of some kind. Online groups have the potential to serve individuals who are unwilling to participate in a face-to-face group as well as those who are unable to do so. There are many cancer support groups available on the Internet at no charge, and many of these are moderated by a professional or peer leader. The information in this chapter is designed to assist facilitators in forming and leading online support groups.

Important note: A great deal of good and helpful information is available on the Internet. Be sure to evaluate any Web sites to which you refer clients or that you intend to use as a sponsoring Web site for your own online group.

Online groups have the potential to serve individuals who are unwilling to participate in a face-to-face group as well as those who are unable to do so.

Internet access requires a computer, modem, communications software, and an Internet service provider (see below). You can also access the Internet without a computer; WebTV makes a box that provides access through a television and a regular phone line.

Many public, hospital, or university libraries and social service agencies offer free or low-cost public access to the Internet. Most locations that provide this service have people on hand to assist you.

The following are some Internet service providers:

America Online	www.aol.com
AT&T	www.att.com
CompuServe	www.compuserve.com
EarthLink	www.earthlink.net
WebTV	www.webtv.com

Format of Group

Before contacting potential participants, decide whether the group format will be a chat group, a bulletin board group, or a mailing list group. Before the group begins, decide what the duration of the group will be, and share the intended guidelines with participants. For time-limited groups, a three-month period is optimal, but the length of the group cycle may be extended if circumstances warrant such an extension.

Types of Online Group Formats

Online groups can be conducted in three different ways.

Chat group (also known as chat room). A chat group is a real-time exchange in which all participants are at their computers at the same time, communicating with each other. Chats are much like a telephone conference call. At a predetermined time, the members sign into the group using a special chat program that allows them to communicate with each other.

- An example of a chat program is ICQ (www.icq.com).
- An example of an online chat can be found at The Cancer Group (www.cancergroup.com/chatroom.html).

Bulletin board (also known as a message board). A bulletin board is a program (usually a location on the World Wide Web) in which participants can read and write messages at any time that can be read by any other participant. The messages remain for the duration of the group, are posted sequentially, and usually are organized by topic.

- An example of a bulletin board program is Ultimate Bulletin Board (www.ubbcentral.com).
- An example of a bulletin board can be found at the American Cancer Society home page (www.cancer.org).

Mailing lists (also known as a list server or listserv). A mailing list is a private email subscription in which each subscriber receives a separate copy, via email, of each message that is posted. Through these messages, members can maintain ongoing communication with other list members who share a particular diagnosis or common concern. A mailing list program forwards messages to the group automatically as soon as they are posted.

- An example of a listserv program is Lyris (www.lyris.com).
- An example of a mailing list can be found at the Association of Cancer Online Resources (www.medinfo.org).

Note: The easiest way to organize a mailing list is to use your own email address book with the names of all group members, then forward each member's messages to the other group members. The facilitator has ultimate control over who is in the group, and the transfer of messages depends on his or her schedule. This method has less security and fewer password protections compared with that provided by chat rooms and bulletin boards.

Electronic Mail (email)

Email, the most popular feature of the Internet, allows individuals to send electronic messages to each other. Email originally was designed for one-to-one communication, but its use is necessary for participation in a mailing list group, in which messages are sent to many people simultaneously.

Free email accounts are available through Juno (http://www.juno.com/), Yahoo!Mail (http://www.yahoo.com/), or Hotmail (http://www.hotmail.com/). Each company will provide you with your own email address and email software.

Recruitment, Screening, and Assessment

Online group facilitators can recruit participants from hospitals, clinics, community organizations, or their own agencies. A statement of the proposed format, guidelines, and duration of the group, as well as what is expected from participants, can be sent out via regular mail as an announcement or brochure. The group facilitator should consider providing all information about the group, including requests for applications, on a Web site, if one is available for use. (For an example, see www.cancercare.org/services/online3.htm.)

All email exchanges between the facilitator and potential group members should remain confidential. Participants should be required to respect the rules of confidentiality, commit to involvement for the duration of the group, and send a minimum number of messages each week. Anonymous groups, in which the facilitator does not know the identity of and other information about participants, should be discouraged.

Screenings can take place by email or by telephone. During the application and screening process, all applicants must provide the following information to the facilitator: real name, address, and phone number; the cancer diagnosis and treatment information if the applicant is the person with cancer; the loved one's cancer diagnosis and treatment information if the applicant is a caregiver; the date and nature of the loved one's death if the applicant is bereaved; previous group and/or individual psychotherapy experiences; and topics and issues the applicant wishes to explore in the group. Knowing about cancer diagnosis, treatment, and support systems (if the group participant is a patient or loved one) or cancer information and date of death (if group member is a bereaved person) can be important in the screening process. The facilitator can use this information to help in the assessment, to know that the person is able to verbalize his or her experiences and concerns, and to ensure that the group composition is maintained within the guidelines set up beforehand.

People who wish to join an online support group must be able to write and express themselves adequately in order to participate. This ability can be assessed via email responses to screening questions posed by the facilitator.

Practical Matters

The size of an online group is important and is dependent on the format used. Chat groups should be small; a maximum of eight participants is ideal. Because of the real-time nature of chat communication, conversations can occur quickly. Having more than eight members involved at one time will prevent the group discussion from achieving any depth or focus. A bulletin board group can accommodate 12 to 15 members. A larger group could prevent the facilitator and members from reading and responding to all the messages posted. A mailing list support group can accommodate up to 25 members without sacrificing intimacy and connectedness. A mailing list educational group can accommodate more than 25 participants.

Starting the Group

You may wish to provide written instructions and group guidelines by email, regular mail, or on a Web site before the start of a time-limited group or when a new member joins an ongoing group. With the group's permission, you may also provide a list of the members and their addresses and phone numbers and encourage members to socialize by telephone between sessions, if this is part of the group norm you envisioned. Any message to a bulletin board or mailing list group will automatically have the member's email address as well as the date and time of day the message was submitted.

The level of intimacy and trust can be greater than in face-to-face groups because of the relative anonymity of an online group.

Online support group participants often develop personal relationships with each other and may wish to have contact outside of the group. In such cases, the facilitator can request that group business be discussed only in the group sessions and can remind participants to maintain the confidentiality of the others.

Participants who have been screened and accepted into a bulletin board or mailing list group have access to the group 24 hours a day, seven days a week for the duration of the group. They should be encouraged to send as many messages as they would like as long as the messages are on topic. Because anything can happen in an online group in any 24-hour period, it is very important for the facilitator to log in at least once daily in order to read, respond, and mediate.

Group Management Issues

Online support groups can be time-consuming for both the facilitator and members because of the number of messages that must be read. Not only does management of an online group require clinical skills, but it also requires some technical skills.

Online support groups provide many benefits. The level of intimacy and trust can be greater than in face-to-face groups because of the relative anonymity of an online group. Participants may feel more comfortable disclosing and discussing their concerns with relative strangers. Because online support groups have no time restrictions as do face-to-face groups, participants can devote more time to their communications and send messages that are rich and meaningful.

In online support groups, the facilitator and group members do not have the benefit of the visual and verbal cues that occur in a face-to-face group. The facilitator of an online group must “listen” in a different way:

by paying close attention to language, to the way group members write, and to the ways in which they express themselves when they are feeling well versus when they are upset or sick. Sometimes facilitators of online groups must be more active and directive than they would be in face-to-face groups, to make up for the lack of eye contact and body language. Participants often consider facilitators who do not send messages to the group on a regular basis to be detached or absent from the group.

The biggest challenge faced by an online group facilitator is the text-based nature of the group environment. The written word, in or out of the context of group communication, can be stark and direct. Humor and sarcasm can be easily misinterpreted, and feelings can be hurt. Therefore, the facilitator must be a strong presence to mediate and guide the group through any conflict.

Working with online cancer support groups poses many challenges for both professional and peer facilitators. However, the benefits groups offer to participants who would not otherwise have access to such information and support make online groups a valuable resource.

6

Evaluation

Documentation and evaluation of support group activity are problems in many institutions. For some reason, these tasks have never been as compelling as the mandate for documentation on an individual patient's medical chart, for instance. Group facilitators may keep notes on group sessions, but these are rarely shared with the rest of the health care team in any formal way. Needless to say, this omission causes support groups to lose credibility as a psychosocial intervention. The lack of a formal documentation system may contribute to the perception that group support is purely a social experience or a demonstration of an institution's interest in its own marketability. In fact, support groups represent a legitimate strategy to help people cope with the cancer experience. Documentation is also important in terms of accountability. Because clinicians within an institution are accountable for the quality of their work, their performance as group facilitators should be included among their activities that merit evaluation.

The most obvious explanation for failure to document group activity pertains to time constraints. If a social worker or nurse is facilitating a 12-member support group for an eight-week period of time, what expectations about adequate documentation are appropriate and realistic? Should the activities and feelings of every person be documented after every session? Or would a summary of each individual's experience be adequate at the completion of the group? If given a choice, most people would choose the latter option. The point is that some attempt should be made to examine this issue, and an institutional policy that safeguards the interests of patients should be established. The purpose of any documentation system is to comply with the professional mandate to deliver high-quality care that is appropriate to the needs of the people it serves.

Do participants receive the support, information, and guidance they expect from the group? How does joining the group affect their lives or relationships with their friends and family?

Documentation also makes it possible to track the support group process and to learn from it. It is very easy to lose sight of the nuances of the process if there is no organized way to evaluate it. The absence of an opportunity to learn from the clinical experience deprives people of their right to the highest quality of care and the most positive outcomes possible. Although documentation and evaluation are important for individual clinicians and the institutions that employ them, it is also important for state-of-the-art psychosocial care. Improving professional practices is virtually impossible without accountability to the people served, the work place, and the profession. Non-professional self-help group facilitators may not have the same concerns about institutional accountability, but they certainly want their groups to be as productive as possible. For this reason, non-professionals also should use documentation for their groups in ways similar to those recommended for professional facilitators.

Regardless of the type of group, the most obvious reason for evaluation is to determine whether it meets the needs of its members. Do participants receive the support, information, and guidance they expect from the group? How does joining the group affect their lives or relationships with their friends and family? Frequent evaluation and documentation of the changing attitudes of participants help keep the facilitator on track. Asking members to fill out a questionnaire is a good way to accomplish this goal.

It is equally important for facilitators to keep their own written records of the group's activity. Such record keeping helps identify any problems or recurring themes. For example, if, while reviewing past summary forms, you notice that a certain member has mentioned a problem with her daughter during several meetings, you can plan to discuss family issues at the next meeting. The evaluation guidelines and questionnaires presented here are meant to be flexible and are offered as examples. They are not a mandate, but are strongly recommended for keeping track of members' needs and monitoring how the structure and format of the group affects member satisfaction and accountability.

The Evaluation of Satisfaction questionnaire (appendix A) provides feedback to the facilitator regarding a participant's satisfaction with the group. Members evaluate both the group experience and the quality of leadership.

The data from this questionnaire give the facilitator a mechanism for determining whether the needs of the group participants are being addressed and helps guide decisions to modify, improve, or expand the program. Because the forms are not signed, members can express their opinions knowing that their answers will not affect their participation in the group or the leader's perception of them.

This questionnaire should be completed at the conclusion of the first group session, midway through the group cycle, at the conclusion of the final group session, or when a participant leaves the group. Evaluation of a group in the middle of its cycle gives the facilitator an opportunity to make changes if members are dissatisfied or if something about the process needs rethinking.

The Facilitator Group Summary form (appendix B) can be used by facilitators to document group activity. The facilitator should record the topics discussed in the sessions and any other relevant observations (e.g., Susan is always late, John is domineering, etc.)

This information helps the facilitator identify any recurrent problems so that assistance can be provided. It also points to any structural changes that may be needed.

It is strongly recommended that the facilitator complete this form at the conclusion of each group meeting so that the information will not be forgotten.

Appendix C is a sample of a form that can be used to document the progress and needs of individuals in a support group. This form can be modified to respond to institutional documentation policies but is offered as an example of a method for providing feedback to members of the health care team who are interested in their patient's psychosocial status. Facilitators may want to use it, or something like it, to demonstrate the impact of support group participation, to improve collaboration with other team members, and to monitor their own professional practice and accountability to standards of care appropriate to their discipline.

Resources

American Cancer Society Resources

The American Cancer Society (the Society) is the nationwide, community-based voluntary-health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service to cancer patients, survivors, and their families. The Society provides educational materials and information on cancer, offers a variety of patient programs, and directs people to services in their community. To find your local office, contact us at 800-ACS-2345 or visit our Web site (www.cancer.org). The Society Web Site provides information on all types of cancer, cancer research, treatment, support groups, and local community resources for cancer patients and their families.

Cancer Survivors Network^{SM}
www.cancer.org
(877) 333-HOPE (1-877-333-4673)

The American Cancer Society's Cancer Survivors Network (CSN) is an online support network created by and for cancer survivors, caregivers, and family members. This services is free and available 24 hours a day, seven days a week. ***Services***: CSN is a virtual community of thousands of registered users who complete profiles, create personal home pages, search and find people like themselves, and communicate with one another through secure CSN email, private chat rooms, and discussion groups. Users also can submit recommended resources and post art, poems, cartoons, etc. on the Expressions Gallery. Web components offer more than 150 hours of prerecorded content of survivors and caregivers telling their personal stories or participating in talk radio discussions. Users can download audio or text versions. Some stories and shows are available in Mandarin, Cantonese, and Spanish by native-speaking survivors.

I Can Cope®
1-800-ACS-2345
www.cancer.org

I Can Cope is a free, educational program provided in a supportive environment for adults with cancer and their loved ones. The program offers several courses conducted by trained health care professionals that are designed to help participants cope with their current experience by increasing their knowledge, positive attitude, and skills. ***Services***: Offers cancer information and answers to questions about human anatomy, cancer development, diagnosis, treatment, side effects, nutrition, pain, management, and community resources. The program also provides information, encouragement, and practical hints through presentations and class discussions.

Look Good…Feel Better®
c/o American Cancer Society
1599 Clifton Road, NE
Atlanta, Georgia 30329
(800) 395-LOOK (1-800-395-5665)
Email: lookgoodfeelbetter@ctfa.org
Web site: www.lookgoodfeelbetter.org
Spanish: www.lookgoodfeelbetter/sp

This free program is offered in partnership with the American Cancer Society, the National Cosmetology Association, and the Cosmetic, Toiletry, and Fragrance Association Foundation. ***Services***: Helps women undergoing cancer treatment improve the appearance-related side effects of treatment. Programs are offered nationwide through the American Cancer Society.

Man to Man®
1-800-ACS-2345
www.cancer.org

Man to man helps men with prostate cancer throughout the continuum of their prostate cancer experience. ***Services***: Provides education and support to men with prostate cancer and their family members. Also conducts community education about prostate cancer, encouraging men and health care professionals to actively consider screening for prostate cancer appropriate for each man's age and risk.

Reach to Recovery®
1-800-ACS-2345
www.cancer.org

For more than 30 years, the American Cancer Society's Reach to Recovery program has been helping breast cancer patients (female and male) cope with their breast cancer experience. Through face-to-face visits or by phone, specially-trained Reach to Recovery volunteers provide support for people with breast cancer. Volunteers are breast cancer survivors. ***Services***: Volunteers provide support and up-to-date information, including literature for spouses, children, friends, and other loved ones. Volunteers can also, when appropriate, provide breast cancer patients with a temporary breast form and information on types of permanent prostheses as well as lists of where those items are available within a patient's community.

Road to Recovery®
1-800-ACS-2345

The American Cancer Society's Road to Recovery program provides transportation for cancer patients to and from related medical/treatment appointments. Rides are provided by volunteer drivers who donate their time and use of their personal vehicles. ***Services***: Road to Recovery is offered to those who have no means of transportation and/or who are too ill to drive themselves. It offers assistance to patients who might otherwise not be able to keep their treatment appointments. Call 1-800-ACS-2345 to find out if Road to Recovery is available in your community.

***"tlc"*™**
1-800-850-9445 (to request a copy of *"tlc"*)
www.tlccatalog.org

"tlc," or Tender Loving Care®, is a "magalog" (magazine/catalog) that combines helpful articles and information with products for women coping with cancer or any cancer treatment that causes hair loss. ***Services***: Access to cancer-related products that include wigs, hairpieces, breast forms, prostheses, bras, hats, turbans, swimwear, and helpful accessories at the lowest possible prices.

Other Resources

The following listings represent organizations that operate on a national level and provide some type of service or resource to consumers.

Most of the organizations listed here can be contacted via phone, fax, or email, and some through their Web site. Many of the Web sites provide much of the same information that is available by postal mail. Some organizations are solely Web-based and will require Internet access. Keep in mind that new Web sites appear daily while old ones expand, move, or disappear entirely. Some of the Web sites or content outlined below may change. Often a simple Internet search will point you to the new Web site for a given organization. The American Cancer Society Web site (www.cancer.org) provides links to outside sources of cancer information and more.

Health Information on the Internet
There is a vast amount of information about cancer on the Internet. This information can be very valuable to those making decisions about their health. However, since any group or individual can publish on the Internet, it is important to consider the credentials and reputation of the organization providing information.

The American Cancer Society does not necessarily endorse the agencies, organizations, corporations, and publications listed in this resources guide. This guide is provided for assistance in obtaining information only.

Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE)
1155 21st Street NW, Suite 350
Washington, D.C. 20036
Lung Cancer Hotline: (800) 298-2436
Email: info@alcase.org
Web site: www.alcase.org

ALCASE is an advocacy, support, and education organization that helps people with lung cancer and their families. ***Services:*** Toll-free telephone support and information, a quarterly newsletter, customized information services, and a resource list.

American Association of Sex Educators, Counselors, and Therapists
P.O. Box 5488
Richmond, Virginia 23220-0488
Email: aasect@aasect.org
Web site: www.aasect.org

A professional organization that provides the names of licensed sex therapists and counselors. Write, email, or visit their Web site for more information. ***Services:*** Helps patients locate therapists, counselors and educators in their area, provides information on human sexuality and valuable links and resources on sexual health.

American Brain Tumor Association
2720 River Road
Des Plaines, Illinois 60018
(800) 886-2282, (847) 827-9910
Email: info@abta.org
Web site: www.abta.org

A national organization that helps people with brain tumors and funds research. ***Services:*** A listing of support groups, telephone consultations, a newsletter, and information on treatment facilities.

American Chronic Pain Association (ACPA)
P.O. Box 850
Rocklin, California 95677
(800) 533-3231
Email: acpa@pacbell.net
Web site: www.theacpa.org

A self-help organization that offers educational material and peer support to help people combat, cope with, and/or live with chronic pain. Call or visit their Web site for a support group in your area. ***Services:*** Provides lists of health care programs and support groups for people with chronic pain, and offers information on managing chronic pain.

American Foundation for Urologic Disease (AFUD)
1000 Corporate Boulevard, Suite 410
Linthicum, Maryland 21090
(800) 828-7866, (410) 689-3990
Email: admin@afud.org
Web site: www.afud.org

AFUD provides information and support groups for people with prostate cancer and their families, and information on urologic disorders. ***Services:*** A toll-free phone line, information on urologic disorders, such as incotinence, impotence, infertility, and kidney health, and a resource guide on prostate cancer.

American Pain Society
4700 West Lake Avenue
Glenview, Illinois 60025
(847) 375-4715
Email: info@ampainsoc.org
Web site: www.ampainsoc.org

Offers up-to-date information on pain-related research, education, treatment and professional services. ***Services:*** Publishes the Pain Facilities Directory with information on more than 500 specialized pain treatment centers across the country.

American Self-Help Clearinghouse
St. Clare's Health Services
25 Pocono Road
Denville, New Jersey 07834
(973) 625-3073
Web site: www.mentalhelp.net/selfhelp

Maintains information on more than 4,000 local self-help meetings throughout New Jersey, and some 800 national self-help and one-of-a-kind groups. ***Services***: Provides information on national self-help groups and offers training and technical assistance to existing and new self-help groups and clearinghouses. Publishes The Self-Help Sourcebook (available online), a listing of national group headquarters, model self-help groups, information on starting groups, and the availability of online computer support groups.

Brain Tumor Foundation for Children, Inc.
1835 Savoy Drive, Suite 200
Atlanta, Georgia 30341
(770) 458-5554
Email: btfc@bellsouth.net
Web site: www.btfcgainc.org

Provides information and patient services for children with brain tumors. ***Services:*** Family support and education programs and activities, public awareness and awareness of brain tumors in children, parent email list and link-up, scholarships, financial assistance to patients in Georgia, and funding for research.

Brain Tumor Society
124 Watertown Street, Suite 3-H
Watertown, Massachusetts 02472
(800) 770-TBTS (8287), (617)-924-9997
Email: info@tbts.org
Web site: www.tbts.org

Provides patient/family information and professional support via toll-free phone line; runs a patient/family network of peer-support volunteers. ***Services:*** Educational materials for patients and physicians, a resource guide, brochures for newly diagnosed patients, and funding for research grants and an annual educational symposium.

BMT InfoNet
2900 Skokie Valley Road, Suite B
Highland Park, Illinois 60035
(888) 597-7674; (847) 433-3313
Email: help@bmtnews.org
Web site: www.bmtnews.org

A nonprofit organization that provides information and services to the transplant community. ***Services:*** A quarterly newsletter, books, listing of transplant facilities, survivor support to transplant patients, drug database, news, and a resource directory for helpful information, financial aid, or emotional support.

Cancer Care, Inc.
275 Seventh Avenue
New York, New York 10001
(800) 813-HOPE (4673); (212) 302-2400
Email: info@cancercare.org
Web site: www.cancercareinc.org

A national organization that helps people with cancer and their families. ***Services:*** Social workers, support groups, educational programs, help for professionals, resources such as drug database, financial assistance, patient-to-patient network bookstore, transportation, and others, telephone education workshops, educational and treatment information, and a newsletter.

Cancer Hope Network (formerly CHEMOcare)
Two North Road
Chester, New Jersey 07930
(877) HOPENET (467-3638)
Email: info@cancerhopenetwork.org
Web site: www.cancerhopenetwork.org

Offers one-to-one support to people undergoing chemotherapy and/or radiation therapy by trained volunteers who have undergone treatment themselves. ***Services:*** Newsletter, volunteer training, peer counseling.

Cancer Information Service (CIS)
NCI Public Inquiries Office
6116 Executive Boulevard, Room 3036A
Bethesda, Maryland 20892-8322
(800) 4-CANCER (422-6237); TTY: 1-800-332-8615
Cancer Fax: (301) 402-5874
Email: cancer.gov_staff@mail.nih.gov
Web site: www.cancer.gov

CIS is a program of the National Cancer Institute (NCI), a US government agency. ***Services:*** National information number for people with cancer, their families, and health care professionals; up-to-date information about cancer and cancer research in both English and Spanish, free of charge, on their Web site and by mail. Regional offices refer people to local cancer-related services and resources.

Cancervive, Inc.
11636 Chayote Street
Los Angeles, California 90049
(800) 4-TO-CURE (800-486-2873); (310) 203-9232
Email: cancervivr@aol.com
Web site: www.cancervive.org

Helps cancer survivors overcome the challenges of life after cancer. ***Services:*** Support groups, fundraising, insurance and legal information and assistance, and advocacy for cancer survivors.

Candlelighters Childhood Cancer Foundation
National Office
P.O. Box 498
Kensington, Maryland 20895-0498
(800) 366-CCCF (800-366-2223); (301) 962-3520
Email: staff@candlelighters.org
Web site: www.candlelighters.org

Provides help to children with cancer and their families. ***Services:*** A network of peer-support groups for parents, a youth newsletter, treatment information, a bibliography of cancer-related materials, summer camp for kids with cancer, bereavement counseling, and advocacy activities.

Center for Attitudinal Healing
33 Buchanan Drive
Sausalito, California 94965
(415)-331-6161
Email: home123@aol.com
Web site: www.attitudinalhealing.org

Provides nonsectarian spiritual and emotional support. ***Services:*** Group counseling and support services for adults and children undergoing life-threatening illnesses or other crises, one-to-one counseling and visitation, referrals, volunteer services, and a speakers' bureau.

Children's Brain Tumor Foundation
274 Madison Avenue, Suite 1301
New York, New York 10016
(866) 228-HOPE (866-228-4673); (212) 448-9494
Email: info@cbtf.org
Web site: www.cbtf.org

Nonprofit organization that funds basic research on pediatric brain tumors. ***Services:*** Support group and network for parents, funds grants for research, provides a free resource guide, and organizes advocacy activities and volunteer services.

EncorePlus® – A Program of the YWCA USA
1015 Eighteenth Street, NW, Suite 1100
Washington, DC 20036
(202) 467-0801
Email: info@ywca.org
Web site: www.ywca.org

Aids women in need of early cancer detection education, breast and cervical cancer screening, and support services. ***Services:*** Peer-group support and exercise programs. Contact your local YWCA.

Genetic Alliance, Inc.
4301 Connecticut Avenue NW, Suite 404
Washington, DC 20008-2369
(800) 336-GENE; (202) 966-5557
Email: information@geneticalliance.org
Web site: www.geneticalliance.org

Helps people with genetic disorders (for example, cystic fibrosis) find support groups and other forms of assistance. ***Services:*** Monthly newsletter, operates the Genetic Education and Resource Center, and provides genetic information and resources.

Gilda Radner Familial Ovarian Cancer Registry
Roswell Park Cancer Institute
Elm and Carlton Streets
Buffalo, New York 14263
(800) OVARIAN (800-682-7426); (716) 845-4503
Web site: www.ovariancancer.com

Collects data on the link between heredity and ovarian cancer. ***Services:*** Ovarian cancer information, help line, newsletter, general counseling, support groups and assistance with genetic screening, and supports research. Note: This is not a treatment center.

The Group Room Radio Talk Show
Vital Options International, Inc.
15821 Ventura Boulevard, Suite 645
Encino, California 91436-2946
(800) GRP-ROOM (800-477-7666; (818) 788-5225
Email: info@vitaloptions.org
Web site: www.vitaloptions.org

A weekly syndicated call-in cancer talk show linking patients, survivors, and health care professionals. Call or visit their Web site for a station in your area, or listen via the Web. ***Services:*** Available in English, French, and German, the program address such relevant and topical issues as nutrition, clinical trials, sexuality, intimacy, and fertility for people living with cancer.

International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, California 91607
(800) 452-CURE (800-452-2873)
Email: theIMF@myeloma.org
Web site: www.myeloma.org

Provides up-to-date information and services for the treatment and management of multiple myeloma. ***Services:*** Toll-free hotline, patient and family seminars, workshops, and seminars, clinical conferences, a quarterly newsletter, and also funds research.

Let’s Face It
P.O. Box 29972
Bellingham, Washington 98228
(360) 676-7325
Email: letsfaceit@faceit.org
Web site: www.faceit.org

A nonprofit organization that helps people with facial disfigurements. ***Services:*** Annual resource directory and self-help network book, online information, and lists of resources.

Leukemia & Lymphoma Society (LLS)
(formerly Leukemia Society of America)
1311 Mamaroneck Avenue
White Plains, New York 10605
(800) 955-4572; (914) 949-5213
Email: infocenter@lls.org
Web site: www.lls.org

A national agency fighting leukemia and all lymphomas (including Hodgkin disease, non-Hodgkin lymphoma, and multiple myeloma). ***Services:*** Support groups, financial assistance, advocacy efforts, funding research, speaker's bureau, professional education programs, and toll-free number for information and resources. LLS has many local chapters.

Lymphoma Research Foundation
8800 Venice Boulevard, Suite 207
Los Angeles, California 90034
(800) 500-9976; (310) 204-7040
Email: lrf@lymphoma.org or helpline@lymphoma.org
Web site: www.lymphoma.org

Provides grants and awards for lymphoma research and support services for lymphoma patients and their families. ***Services:*** Support groups, toll-free helpline and clinical trials information service, conferences, financial inquiries and insurance assistance, continuing education for health care professionals, fundraising events, and advocacy activities.

Mautner Project for Lesbians with Cancer
1707 L Street, NW, Suite 230
Washington, DC 20036
(202) 332-5536
Email: mautner@mautnerproject.org
Web site: www.mautnerproject.org

Provides services and support to lesbians who have cancer, their partners, and their families. ***Services:*** Advocating for benefits, volunteer services, transportation to and from treatment, legal assistance, bereavement counseling, support groups, referrals to sensitive professionals, and a resource center.

National Brain Tumor Foundation
22 Battery Street, Suite 612
San Francisco, California 94111
(800) 934-CURE (800-934-2873); (415) 834-9970
Email: nbtf@braintumor.org
Web site: www.braintumor.org

Provides information, counseling, and support services to brain tumor patients and their families. ***Services:*** Newsletter, patient-to-patient telephone support line, message boards, free resource guide, list of support groups, and also funds research.

National Cancer Institute (NCI)
NCI Public Inquiries Office
6116 Executive Boulevard, Room 3036A
Bethesda, Maryland 20892-8322
(800) 4-CANCER (422-6237); TTY: 1-800-332-8615
Cancer Fax: (301) 402-5874
Email: cancer.gov_staff@mail.nih.gov
Web site: www.cancer.gov

The US government agency responsible for conducting and supporting research on cancer. ***Services:*** The Physicians Data Query (PDQ), an up-to-date listing of cancer information and resources, toll-free cancer information hotline, and Cancer Fax.

National Coalition for Cancer Survivorship
1010 Wayne Avenue, Suite 770
Silver Spring, Maryland 20910
(877) NCCS-YES (877-622-7937); (301) 650-9127
Email: info@canceradvocacy.org
Web site: www.canceradvocacy.org

A network of groups and individuals promoting national awareness of issues affecting cancer survivors and the development of support services for them. ***Services:*** Advocacy and public education, audio and text resources, webcasts, and publications.

National Family Caregivers Association
10400 Connecticut Avenue, #500
Kensington, Maryland 20895
(800) 896-3650
Email: info@nfcacares.org
Web site: www.nfcacares.org

Provides education, support, respite care, and advocacy for caregivers. ***Services:*** Counseling, support groups, professional education, and a toll-free information line.

National Hospice and Palliative Care Organization
1700 Diagonal Road, Suite 625
Alexandria, Virginia 22314
(800) 658-8898; (703) 837-1500
Email: nhpco_info@nhpco.org
Web site: www.nho.org

Provides information and referrals to local hospice programs via toll-free number. ***Services:*** Referrals to hospice programs, patient advocacy, and professional education.

National Ovarian Cancer Coalition
500 NE Spanish River Boulevard, Suite 8
Boca Raton, Florida 33431
(888) OVARIAN (888-682-7426); (561) 393-0005
Email: NOCC@ovarian.org
Web site: www.ovarian.org

Promotes education about ovarian cancer to the public and the medical community. ***Services:*** Support groups, patient advocacy, toll-free ovarian cancer information line.

National Self-Help Clearinghouse
Graduate School and University Center of the City University of New York
365 Fifth Avenue, Suite 3300
New York, New York 10016
(212) 817-1822
Email: info@selfhelpweb.org
Web site: www.selfhelpweb.org

Provides information and referrals to self-help, mutual support groups, and other community resources across the country. ***Services:*** Provides speakers, manuals, monographs, and policy papers. Also provides training and consultations for group leaders and professional facilitators.

Oley Foundation, Inc.
214 Hun Memorial, A-28
Albany Medical Center, A-23
Albany, New York 12208
(800) 776-OLEY (800-776-6539); (518) 262-5079
Email: bishopj@mail.amc.edu
Web site: http://c4isr.com/oley/

Provides help to patients who require long-term, specialized nutritional therapy. ***Services:*** Counseling, support groups, entitlement benefits and insurance information, advocacy, outreach, a newsletter and other publications, and a research registry.

Sisters Network, Inc.
8787 Woodway Drive, Suite 4206
Houston, Texas 77063
(713) 781-0255
Email: infonet@sistersnetworkinc.org
Web site: www.sistersnetworkinc.org

The first national breast cancer survivors support group organized for African American women. ***Services:*** Community education and awareness programs, person-to-person support, speakers bureau, and a national newsletter. Call or visit their Web site for local chapter information.

Support for People with Oral and Head and Neck Cancer (SPOHNC)
P.O. Box 53
Locust Valley, New York 11560-0053
(800) 377-0928
Email: info@spohnc.org
Web site: www.spohnc.org

A patient-run support group program (with local chapters) for people who have or have had oral, head, or neck cancers. ***Services:*** Small group meetings, patient networking, nationwide newsletter, library, insurance information and assistance, and information packet (text or online).

Susan G. Komen Breast Cancer Foundation
5005 LBJ Freeway, Suite 250
Dallas, Texas 75244
(800) IM AWARE (800-462-9273); (972) 855-1600
Email: helpline@komen.org
Web site: www.komen.org

Dedicated to eradicating breast cancer as a life-threatening disease through research, education, screening, and treatment. ***Services:*** Helpline staffed by trained volunteers, funds research, and fundraising for other cancer-related programs through a major event (Race for the Cure®) and products.

United Ostomy Association, Inc.
19772 MacArthur Boulevard, Suite 200
Irvine, California 92612-2405
(800) 826-0826; (949) 660-8624
Email: info@uoa.org
Web site: www.uoa.org

An association of ostomy chapters dedicated to complete rehabilitation of all ostomates (people who have ostomies). Call or visit their Web site for a listing of local chapters. ***Services:*** Cancer counseling, advocacy activities, self-help, materials and publications, information about ostomy supplies, conferences, and peer groups.

US TOO! International, Inc.
5003 Fairview Avenue
Downers Grove, Illinois 60515
(800) 80-Us TOO (800-808-7866); (630) 795-1002
Email: ustoo@ustoo.org
Web site: www.ustoo.org

An international network of chapters providing support and services to prostate cancer survivors. Call or visit their Web site for support group information and/or local chapters. ***Services:*** General information and treatment information, support groups, advocacy efforts, volunteer opportunities, and events.

Well Spouse Foundation
63 West Main Street, Suite H
Freehold, New Jersey 07728
(800) 838-0879; (732) 577-8899
Email: info@wellspouse.org
Web site: www.wellspouse.org

A membership organization providing support and information to the "well spouse" of the chronically ill. ***Services:*** Newsletter, local support groups, mentorship program, an annual weekend conference, and bereavement counseling.

Wellness Community
919 Eighteenth Street, NW
Washington, DC 20006
(888) 793-WELL (888-793-9355); (202) 659-9709
Email: help@thewellnesscommunity.org
Web site: www.thewellnesscommunity.org

A national nonprofit organization that provides free psychosocial support to people recovering from cancer. Call or visit their Web site for a local chapter. ***Services:*** Professionally led and online support groups, educational workshops, and mind/body programs.

Y-Me National Breast Cancer Organization
212 West Van Buren, Suite 1000
Chicago, Illinois 60607-3908
(800) 221-2141 (24-hour English hotline);
(800) 986-9505 (Spanish); (312) 986-8338
Email: askyme@y-me.org
Web site: www.y-me.org

Provides support to individuals concerned about or diagnosed with breast cancer. ***Services:*** Toll-free hotline staffed by trained counselors and volunteers who have had breast cancer. Male callers can request a male counselor; publications and resource library, support services, educational programs, clinical trial information, and wig bank. Call or visit their Web site for local chapters.

General Information

Books

Cancer Care, Inc. *The Helping Hand – A Resource Guide for People with Cancer.* New York: Cancer Care, Inc. *The Helping Hand Resource Guide* tells what types of help are available to people with cancer and where to find them. This resource guide provides general information on cancer and on specific services. It is designed to either answer questions or direct the reader to someone who can. Available online at www.cancercare.org or by calling 1-800-813-HOPE.

Cancer Survival Toolbox™: Building Skills that Work for You. A free, self-learning audio program that covers topics and skills that can help people with cancer, their family members, and caregivers meet the challenge of cancer. These audio cassettes/compact discs are a collaborative undertaking of the Association of Oncology Social Work, the Oncology Nursing Society, and the National Coalition for Cancer Survivorship. Tapes are available in English, Spanish (audio cassettes only), and Chinese (print only). Available for listening online at: www.cancersurvivaltoolbox.org, or can be ordered online at www.cancersurvivaltoolbox/orderForm.aspx or by calling 1-877-TOOLS-4U (1-877-866-5748).

Eyre HJ, Lange DP, Morris LB. *Informed Decisions, Second Edition: The Complete Book of Cancer Diagnosis, Treatment, and Recovery.* Atlanta: American Cancer Society; 2002. Provides the latest information on every aspect of cancer, from detection to recovery, and covers cancer causes and risks, screening and diagnostic tests, treatment strategies, coping tips, and quality of life issues.

Fincannon JL, Bruss KV. *Couples Confronting Cancer: Keeping Your Relationship Strong.* Atlanta, Georgia: American Cancer Society; 2003.

Kelly P. *Cancer Self-Help Groups: A Guide.* Buffalo, New York: Firefly Books; 2000. A manual on creating and maintaining an effective cancer support group, written by and for people with cancer in conjunction with cancer researchers and other experts.

Klein L. *The Support Group Sourcebook: What They Are, How You Can Find One, & How They Can Help You.* New York: John Wiley; 2000.

Kurtz LF. *Self Help & Support Groups: A Handbook for Practitioners.* Thousand Oaks, California: SAGE Publications; 1997.

Lauria MM, Clark EJ, Hermann JF, Stearns NM. *Social Work in Oncology: Supporting Survivors, Families, and Caregivers.* Atlanta: American Cancer Society; 2001. Directed toward social workers new to the oncology field. Presents information about cancer diagnosis and treatment, the ways pediatric and adult patients and their families experience cancer, the range of social work interventions applied in cancer care, professional issues in oncology social work, the identification and access of available resources, and a special patient information section on understanding and using support services.

Nessim S, Ellis J. *Can Survive.* Boston: Houghton Mifflin; 2000. A resource guide that provides strategies for coping with problems that arise after cancer treatment, including fear of recurrence, employment and insurance issues, interpersonal relationships, and long-term effects.

Varricchio CG, Ades TB, Hinds PS, Pierce M, eds. *A Cancer Source Book for Nurses, Eighth Edition.* Sudbury, Massachusetts: Jones and Bartlett Publishers and the American Cancer Society; 2004. A resource for oncology nurses or those nurses new to oncology nursing. Provides information on all types of cancer, treatment approaches, and nursing issues.

Yalom ID. *Theory and Practice of Group Psychotherapy.* Fourth edition. New York: Basic Books; 1995.

Articles

Bottomley A, Hunton S, Roberts G, Jones L, Bradley C. A pilot study of cognitive behavioral therapy and social support group interventions with newly diagnosed cancer patients. *J Psychosoc Oncol.* 1996;14:65-83.

Bottomley A. Cancer support groups – are they effective? *Eur J Cancer Care.* 1997;6:11-17.

Bottomley A. Where are we now? Evaluating two decades of group interventions with adult cancer patients. *J Psychiatr Ment Health Nurs.* 1997;4:251-265.

Carlsson ME, Strang PM. Educational group support for patients with gynaecological cancer and their families. *Support Care Cancer.* 1996;4:102-109.

Evans RL, Connis RT. Comparison of brief group therapies for depressed cancer patients receiving radiation treatment. *Public Health Rep.* 1995:110:306-311.

Fobair P. Cancer support groups and group therapies: part I. Historical and theoretical background and research on effectiveness. *J Psychosoc Oncol.* 1997;15:63-81.

Fobair P. Cancer support groups and group therapies: part II. Process, organizational, leadership, and patient issues. *J Psychosocal Oncol.* 1997;15:123-147.

Grahn G. Coping with the cancer experience: I. Developing an education and support programme for cancer patients and their significant others. *Eur J Cancer Care.* 1996;5:176-181.

Gray RE, Carroll JC, Fitch M, Greenberg M, Chart P, Orr V. Cancer self-help groups and family physicians. Cancer Pract. 1999;7:10-15.

Guidry JJ, Aday LA, Zhang D, Winn RJ. The role of informal and formal social support networks for patients with cancer. *Cancer Pract.* 1997;5:241-246.

Heiney SP, Darr-Hope H. Healing icons: art support program for patients with cancer. *Cancer Pract.* 1999;7:183-189.

Hermann JF, Cella DF, Robinovitch A. Patient resources. Guidelines for support group programs. *Cancer Pract.* 1995;3:111-113.

Montazeri A. A descriptive study of a cancer support group. *Eur J Cancer Care.* 1996;5:32-37.

Roberts CS, Piper L, Denny J, Cuddeback G. A support group intervention to facilitate young adults' adjustment to cancer. *Health Soc Work.* 1997;22;133-141.

Rustoen T, Hanestad BR. Nursing intervention to increase hope in cancer patients. *J Clin Nursing.* 1998;7:19-27.

ten Kroode HF. Active listening to cancer patients' stories. *Neth J Med.* 1998;53:47-52.

Tobia DM, Shamos EF, Harper DM, Walch SE, Currie JL. The benefits of group music at the 1996 music weekend for women with cancer. *J Cancer Edu.* 1999;14:115-119.

Webster A. Complementary & alternative therapies: Mind/Body medicine: self-care skills for persons with cancer. *Cancer Pract.* 1999;7:43-45.

Wolgin F. Incorporating adult learning principles when training cancer support group facilitators. *Dev Support Cancer Care.* 1998;2:50-53.

Children and Cancer

Books

Abelove J. *Saying It Out Loud.* New York: DK Publishing; 1999. (Young adult fiction)

Ackermann A, Ackermann A. *Our Mom Has Cancer.* Atlanta, Georgia: American Cancer Society; 2001.

American Cancer Society. *Because… Someone I Love Has Cancer.* Atlanta, Georgia: American Cancer Society; 2003.

Center for Applied Psychology. *Childswork/Childsplay*. A catalog of games and activities appropriate for use with support programs for children. Available from Childswork/Childsplay, Center for Applied Psychology, P.O. Box 61586, King of Prussia, Pennsylvania 19406. (800) 962-1141 (orders); (610) 277-4177 (customer service).

Center for Applied Psychology. *The Book of Psychotherapeutic Homework.* Available from Childswork/Childsplay, Center for Applied Psychology, P.O. Box 61586, King of Prussia, Pennsylvania 19406. (800) 962-1141 (orders); (610) 277-4177 (customer service).

Center for Basic Cancer Research Staff, KSU Cancer Center. *A Day with Dr. Waddle: An Introduction to Cancer Written for Children.* Manhattan, Kansas: Kansas State University Center; 1988. (Children ages 4-8). Available online at http://www.k-state.edu/cancer.center/drwaddle/index.htm, or call (785) 532-6705, or write to Center for Basic Cancer Research, KSU, Manhattan, Kansas 66506.

Chesler MA, Chesney BK. *Cancer and Self-Help: Bridging the Troubled Waters of Childhood Illness.* Madison, Wisconsin: University of Wisconsin Press; 1995.

Clifford C, Lindstrom J, ill. *Our Family Has Cancer, Too!* Duluth, Minnesota: Pfeifer-Hamilton Publishers; 1998.

Cohen, CK, Heiney JT. *My Daddy's Cancer: An Interactive Book for Children.* Bloomfield Hills, Michigan: Promise Publications; 1999. (Similar title, My Mommy's Cancer, also available.)

Fox Chase Cancer Center. *Talking About Your Cancer: A Parent's Guide to Helping Children Cope* (video). Call (888) FOX-CHASE (888-369-2427) to order.

Fromer MJ. *Surviving Childhood Cancer: A Guide for Families.* Oakland, California: New Harbinger Publications, 1998.

Ganz P, Scofield T, ill. *Life Isn't Always a Day at the Beach: A Book for All Children Whose Lives Are Affected by Cancer.* Lincoln, NE: High Five Publishing; 1996.

Gordon, MA. *Let's Talk About When Kids Have Cancer.* New York: PowerKids Press; 1999.

Harpham WS. *When A Parent Has Cancer: A Guide to Caring for Your Children.* New York: HarperCollins; 1997.

Heiney SP. *Quest: A Journal for the Teenager Whose Parent Has Cancer.* Columbia, South Carolina: Center for Cancer Treatment and Research of Palmetto Richland Memorial Hospital; 2000. To order, call (800) 775-2287.

Heiney SP, Hermann JF, Bruss KV, Fincannon JL. *Cancer in the Family: Helping Children Cope with a Parent's Illness.* Atlanta, Georgia: American Cancer Society; 2001.

McCue K, Bonn R. *How to Help Children Through a Parent's Serious Illness.* New York: St. Martin's Griffin; 1996.

Murray L, Howard B. *Angels & Monsters.* Atlanta, Georgia: American Cancer Society; 2002. (A collection of art, words, and portraits from children who have/had cancer.)

Nessim S, Wyman B. *Draw Me A Picture and A Friend for Life.* Available from Cancervive, Inc. To order, write to 11636 Chayote Street, Los Angeles, CA 90049; call (800) 4-TO-CURE (800-486-2873); or visit their Web site at www.cancervive.org. Children's videos and games are also available.

O'Rourke K, Worzbyt JC. *Support Groups for Children.* Washington, DC: Accelerated Development, 1996.

Pennebaker R. *Both Sides Now.* New York: Holt; 2000. (Young adult fiction)

Ragg M. *Body and Soul: Children, Teenagers & Cancer.* New York: Hill of Content; 1995.

Worden, JW. *Children and Grief: When A Parent Dies.* New York: The Guilford Press; 1996.

Articles

Greening, K. The "Bear Essentials' Program": Helping Young Children and Their Families Cope When a Parent Has Cancer. *Journal of Psychosocial Oncology.* 1992;10:47-61. Available from the Missouri Baptist Medical Center, (314) 569-5517. http://www.bear-essentials.org/BearEssentials.html.

Harpham WS. Resources for helping children whose parent (or other loved one) has cancer. *Cancer Pract.* 1999;7:96-99.

Heiney SP, Lesesne CA. Quest. An intervention program for children whose parent or grandparent has cancer. *Cancer Pract.* 1996;4:324-329.

Bereavement

Abrahm JL, Cooley M, Ricacho L. Efficacy of an educational bereavement program for families of veterans with cancer. *J Cancer Educ.* 1995;10:207-212.

Goldstein J, Alter CL, Axelrod R. A psychoeducational bereavement support group for families provided in an outpatient cancer center. *J Cancer Educ.* 1996;11:233-237.

Lorenz L. Selecting and implementing support groups for bereaved adults. *Cancer Pract.* 1998;6:161-166. Review.

Caregivers

Gilbar O. Cancer caregiver support group: a model for intervention. *Clin Gerontol.* 1997;18:31-37.

Horowitz S, Passik SD, Malkin MG. "In sickness and in health": a group intervention for spouses caring for patients with brain tumors. *J Psychosoc Oncol.* 1996;14:43-56.

Houts PS, Bucher JA. *Caregiving: A Step-By-Step Resource for Caring for the Person with Cancer at Home, Revised Edition.* Atlanta, Georgia: American Cancer Society; 2003.

Groups for Specific Cancer Sites

Breast Cancer

Ashbury FD, Cameron C, Mercer SL, Fitch M, Nielson E. One-on-one peer support and quality of life for breast cancer patients. *Patient Educ Couns.* 1998;35:89-100.

Burch R. Alive & kicking. *Nurs Times.* 1997;93:26-29.

Cope DG. Functions of a breast cancer support group as perceived by the participants: an ethnographic study. *Cancer Nurs.* 1995;18:472-478.

Curran VR, Church JG. A study of rural women's satisfaction with a breast cancer self-help network. *J Telemed Telecare.* 1999;5:47-54.

Feigin R, Greenberg A, Ras H, et al. The psychosocial experience of women treated for breast cancer by high-dose chemotherapy supported by autologous stem cell transplant: a qualitative analysis of support groups. *Psychooncol.* 2000;9:57-68.

Gray R, Fitch M, Davis C, Phillips C. A qualitative study of breast cancer self-help groups. *Psychooncol.* 1997;6:279-289.

Gray R, Fitch M, Davis C, Phillips C. Breast cancer and prostate cancer self-help groups: reflections on differences. *Psychooncol.* 1996;5:137-142.

Helgeson VS, Cohen S, Schulz R, Yasko J. Education and peer discussion group interventions and adjustment to breast cancer. *Arch Gen Psychiatry.* 1999;56:340-347.

Karp J, Brown KL, Sullivan MD, Massie MJ. The prophylactic mastectomy dilemma: a support group for women at high genetic risk for breast cancer. *J Genet Couns.* 1999;8:163-173.

Krizek C, Roberts C, Ragan R, Ferrara JJ, Lord B. Gender and cancer support group participation. *Cancer Pract.* 1999;7:86-92.

Lee MM, Lin SS, Wrensch MR, Adler SR, Eisenberg D. Alternative therapies used by women with breast cancer in four ethnic populations. *J Natl Cancer Inst.* 2000;92;42-47.

Oliviere D, Golding V. Cancer care in the workplace: the study of a breast cancer support group. *J Cancer Care.* 1996;5:73-78.

Pilisuk M, Wentzel P, Barry O, Tennant J. Participant assessment of a nonmedical breast cancer support group. *Altern Ther Health Med.* 1997;3:72-80.

Samarel N, Fawcett J, Krippendorf K, et al. Women's perceptions of group support and adaptation to breast cancer. *J Adv Nurs.* 1998;28:1259-1268.

Samarel N, Fawcett J, Tulman L. Effect of support groups with coaching on adaptation to early-stage breast cancer. *Res Nurs Health.* 1997;20:15-26.

Sharf BF. Communicating breast cancer online: support and empowerment on the Internet. *Women Health.* 1997;26:65-84.

Stevens MJ, Duttlinger JE. Correlates of participation in a breast cancer support group. *J Psychosom Res.* 1998;45:263-275.

Prostate Cancer

Chin-A-Loy SS, Fernsler JI. Self-transcendence in older men attending a prostate cancer support group. *Cancer Nurs.* 1998;21:358-363.

Coreil J, Behal R. Man to Man® prostate cancer support groups. *Cancer Pract.* 1999;7:122-129.

Gray RE, Fitch M, Davis C, Phillips C. Interviews with men with prostate cancer about their self-help group experience. *J Palliat Care.* 1997;13:15-21.

Gray R, Fitch M, Davis C, Phillips C. Breast cancer and prostate cancer self-help groups: reflections on differences. *Psychooncol.* 1996;5:137-142.

Gregoire I, Kalogeropoulos D, Corcos J. The effectiveness of a professionally led support group for men with prostate cancer. *Urol Nurs.* 1997;17:58-66.

Krizek C, Roberts C, Ragan R, Ferrara JJ, Lord B. Gender and cancer support group participation. *Cancer Pract.* 1999;7:86-92.

O'Rourke ME, Germino BB. Prostate cancer treatment decisions: a focus group exploration. *Oncol Nurs Forum.* 1998;25:97-104.

Other Cancers

Carlsson ME, Strang PM. Educational support programme for gynaecological cancer patients and their families. *Acta Oncol.* 1998;37:269-275.

Leavitt MB, Lamb SA, Voss BS. Brain tumor support group: content themes and mechanisms of support. *Oncol Nurs Forum.* 1996;23:1247-1256.

McGrath P. Findings from an educational support course for patients with leukemia. *Cancer Pract.* 1999;7:198-204.

Sivesind DM, Baile WF. An ovarian cancer support group. *Cancer Pract.* 1997;5:247-251.

Special Interest Groups

Matthews AK. Lesbians and cancer support: clinical issues for cancer patients. *Health Care Women Intl.* 1998;19:193-203. Review.

Miano LY, Rojas MS, Trujillo M. "Platicas y merienda": reaching Spanish-speaking patients in an oncology setting. *Cancer Pract.* 1996;4:199-203.

Weiss JO, Mackta JS. *Starting & Sustaining Genetic Support Groups.* Baltimore, Maryland: Johns Hopkins University Press; 1996.

Telephone Support Groups

Colón Y. Telephone support groups: a nontraditional approach to reaching underserved cancer patients. *Cancer Pract.* 1996;4:156-159.

Rounds KA, Galinsky MJ, Stevens LS. Linking people with AIDS in rural communities: the telephone group. *Soc Work.* 1991;36:13-18.

Resources for Online Groups

Practice Standards for Online Groups

American Counseling Association
www.counseling.org

Ethical standards for the practice of online counseling

International Society for Mental Health Online
www.ismho.org

Suggested principles for providing mental health services online

National Board for Certified Counselors
www.nbcc.org/depts/ethicsmain.htm

Standards for the ethical practice of Web counseling

List Servers and Chat Rooms

Each subscriber to a mailing list, or listserv, receives a separate copy through email of each item that is posted. Mailing lists are an excellent resource for people with cancer who wish to talk to others with the same diagnosis. Through these messages you can establish an ongoing dialogue with other list members. It is not uncommon to receive dozens of messages each day from particularly active mailing lists. The list below is far from complete; the best way to find and subscribe to mailing lists is to go to one of the following:

Association of Oncology Social Work (SWON) (members only)
www.aosw.org/Pages/membership.html

Cancer Survivors Network
www.acscsn.org

Psych Central's Mailing Lists, Newsgroups, and Chat Rooms
www.psychcentral.com

Social Work Access Network Listservs and Chat Rooms
www.sc.edu/swan/

Other Online Resources

Cancer Care Briefs
www.cancercare.org/EducationalPrograms/EducationalPrograms.cfm?ID=3464&c=381

Information about using the Internet to find cancer resources.

International Society for Mental Health Online
www.ismho.org

Promotes online communication for the international mental health community.

Mental Health Net
www.mentalhelp.net

The largest, most comprehensive online guide to mental health.

Psych Central
www.psychcentral.com

Dr. John Grohol's Mental Health Page serves as a comprehensive index for psychology resources, support groups, and mental health issues.

Psychology of Cyberspace
www.rider.edu/~suler/psycyber/psycyber.html

Cyberpsychology resources on the Internet, run by John Suler, PhD.

Stormsite: The Psychology of Virtual Communities
http://webpages.charter.net/stormking/

Storm King's engaging collection of articles about the psychology of cyberspace, cyberspace relationships, and virtual support groups/psychotherapy.

Psychotechnology Online
www.psychotechnology.com or www.jerifink.com

Jeri Fink, DSW, investigates the partnership between psychology and technology.

World Wide Web Resources for Social Workers
www.nyu.edu/socialwork/wwwrsw

Created by Gary Holden, DSW, of New York University to facilitate social workers' access to information available on the Internet.

Print Resources for Internet Resources

Books

Colón Y. Digital digging: Group therapy online. In: Fink, J, ed. *How to Use Computers and Cyberspace in the Clinical Practice of Psychotherapy.* Northvale, New Jersey: Aronson; 1999.

Gackenbach J, ed. *Psychology and the Internet: Intrapersonal, interpersonal, and transpersonal implications.* San Diego, California: Academic Press; 1998.

Grohol JM. *Insider's Guide to Mental Health Resources Online, Rev ed.* New York: Guilford Press; 2004.

LaBruzza A. *The Essential Internet: A Guide for Psychotherapists and Other Mental Health Professionals.* Northvale, New Jersey: Aronson; 1997.

Rosen LD, Weil MM. *The Mental Health Technology Bible.* New York: Wiley; 1997.

Articles

Bliss J, Allibone C, Bontempo B, Flynn T, Valvano NE. Creating a Web site for online social support Melanocyte. *Comput Nurs.* 1998;16:203-207.

Fernsler JI, Manchester LJ. Evaluation of a computer-based cancer support network. *Cancer Pract.* 1997;5:46-51.

Galinsky MJ, Schopler JH, Abell MD. Connecting group members through telephone and computer groups. *Health Soc Work.* 1997;22:181-188.

Klemm P, Hurst M, Dearholt SL, Trone SR. Cyber solace: gender differences on Internet cancer support groups. *Comput Nurs.* 1999;17:65-72.

Klemm P, Reppert K, Visich L. A nontraditional cancer support group. The Internet. *Comput Nurs.* 1998;16:31-36.

Sharf BF. Communicating breast cancer online: support and empowerment on the Internet. *Women Health.* 1997;26:65-84.

Shopler JH, Galinsky Mj, Abell M. Creating community through telephone and computer groups: Theoretical and practical perspectives. *Social Work Groups.* 1997;20:19-34.

Smith J. Members only: electronic support groups closed to the average surfer. *J Natl Cancer Inst.* 1998;90:1696.

Weinberg N, Schmale JD, Uken J, Wessel K. Computer-mediated support groups. *Soc Work Groups*. 1995;17:43-54.

Weinberg N, Schmale JD, Uken J, Wessel K. Online help: cancer patients participate in a computer-mediated support group. *Health Soc Work*. 1996;21:24-29.

APPENDIX A

Evaluation of Satisfaction

Date ____________________

1. How did you learn about the group?
   ☐ A friend ☐ Referred by health care professional
   ☐ Newspaper ☐ Other ______________________________

2. Is this your first meeting? ☐ Yes ☐ No

3. Will you attend future meetings? ☐ Yes ☐ No

4. Please assess the following aspects of the meeting:

	Very Satisfied	Somewhat Satisfied	Not Satisfied
Makeup of meeting (types of members, similarities or differences of members' issues)	☐	☐	☐
Format of meeting (planned agenda, open discussion)	☐	☐	☐
Number of meetings	☐	☐	☐
Length of meetings	☐	☐	☐
Opportunity to talk	☐	☐	☐
Location of the meeting	☐	☐	☐

5. How helpful was the group for you?
   ☐ Not helpful ☐ Somewhat helpful
   ☐ Very helpful ☐ Extremely helpful

6. Describe briefly what was most helpful to you:

7. What did you learn from the group that you wanted to learn?

8. What did you like most about the group?

9. What did you like least about the group?

10. Do you feel any differently about yourself after the group?
   ☐ Yes ☐ No
   If yes, in what ways do you feel different?

11. Has this group changed the way you've dealt with your cancer?
   ☐ Yes ☐ No
   If yes, what has changed?

12. Please comment or provide suggestions for future groups and/or suggestions for improvement.

APPENDIX B

Facilitator Group Summary

Chapter ________________________ Date ______________

Facilitator(s) ______________________________________

Meeting location ____________________________________

Total no. of participants _____________________________

No. of men _______ No. of women _______ No. of patients _______

No. of spouses _______ No. other _______

Frequency of meetings _______________________________

Group format _______________________________________

General discussion ___________________________________

Specific topic _______________________________________

Discuss themes covered in this session and other relevant observations:

Date of next meeting _________________________________

APPENDIX C

Participant Progress Summary: Support Group Intervention

Name ____

Medical record number ______________________________

Number of meetings attended _________________________

Facilitator _______________________________________

Telephone _______________________________________

Identified concerns _________________________________

____

____

____

____

____

____

Assessment and follow up plan ________________________

____

____

____

____

____

____

Signature _______________________________________

Date ____

APPENDIX

APPENDIX

APPENDIX

APPENDIX

APPENDIX

APPENDIX

APPENDIX

APPENDIX

APPENDIX

No.4660-Rev. 12/04

The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

No matter who you are, we can help. Contact us anytime, day or night, for information and support.

American Cancer Society®

1.800.ACS.2345
www.cancer.org

Hope.Progress.Answers.®