Leukemia Support Groups: How Are They Doing?

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Support groups can improve the adjustment of individuals who are coping with cancer diagnosis, treatment, and survival.

**Background:** Support groups help their participants to cope with the emotional and practical impact of their illnesses.

**Methods:** The effectiveness of the Leukemia Society of America support groups in enhancing the quality of life for their participants is reviewed. The groundwork, purpose, and structure of such groups, as well as alternate sources of support, are presented. Evaluation and future directions for oncology group work are discussed.

**Results:** Support groups complement the therapies provided by clinical practitioners and scientists by addressing the additional needs of cancer patients over the course of illness and survival.

**Conclusions:** New concepts and methods that address the needs of specific age groups and incorporate the newly generated data on cancer treatments will further enhance the benefits provided by support groups.

**Introduction**

It has been eight years since Spiegel et al reported that cognitive-behavioral and socially supportive group therapies for patients undergoing cancer treatment resulted in less depression, hostility, anxiety, and somatization among patients when compared to a controlled, no-treatment condition. After six months, participants in social support groups continued to show improvement in their psychosocial functioning. Today, support groups provide advantages for patients that were not possible 10 years ago. Several studies in oncology, many of them well controlled with randomized assignment, show improvements in one or more domains of quality of life that result from participation in a support or skill-training group.

These findings are applicable to patients with hematologic neoplasms. Due in part to effective research over the last 25 years, patients with leukemia, lymphoma, and myeloma are living longer, and they sometimes can support each other for many years. This is often termed the “extended survival” phase of survivorship. The long-term support group can serve the leukemia patient well and should be appreciated from a life-cycle perspective.

**Rationale for Support Groups**

Research on long-term support groups has emphasized the measurable benefits of mutual aid, peer support, and universality. In addition, openly addressing the existential issues related to death and dying, pain, and daily coping is a welcome salve to patients who may feel stigmatized by their illness in their workplace or social systems. In their review of the literature on group work, Fawzy et al found that patients gain from a variety of short-term, structured interventions including health education, stress management, and problem-solving techniques. They support short-term psychoeducational models that provide easily replicated programs for patients who have recently been diagnosed or are at the same stage of illness. The Leukemia Society of America (LSA) has tried to embrace both long- and short-term models that are not mutually exclusive of one another.

Groups that are specific to disease categories have become increasingly popular. Groups have been developed that focus on brain tumors and a variety of other types of cancers, such as breast, lung, prostate, and ovarian. Some theorists suggest that the core concerns, themes, and feelings of cancer support groups are no different from those of groups for other chronic and acute illnesses and thus can serve the needs of many types of patients. Others, however, note that disease-specific groups fulfill a particular need for patients who, in general, have access to specialized information and want to share that information with peers in highly similar situations.

The LSA is involved with more than one disease category; it includes malignancies of the blood, marrow, and lymphatic systems (eg, leukemia, lymphoma, Hodgkin's disease, and myeloma). Leukemia and its related blood cancers have variable courses and prognoses. Thus, groups for the patient with leukemia and related blood cancers must be responsive to issues relating to the entire course of the disease, whether the patient is newly diagnosed with leukemia, is finishing induction chemotherapy, is awaiting a transplant, has undergone a recent transplant, or is experiencing a relapse later in life. In light of the myriad complexities of patient care, the LSA began promoting patient services more than 12 years ago. This effort was bolstered by the LSA's 1993 revised mission statement: "Cure leukemia and related cancers and improve the quality of life of patients and families." The current programs consist of long-term, open-ended groups that usually meet monthly and are
During 1996, 138 professionals volunteered to lead 72 family support groups nationwide, a 40% increase over the previous year. The LSA’s Family Support Group program guidelines emphasized sharing experiences and psychoeducational sessions. Oversight of these groups rested with an advisory committee comprised of health care professionals during a time when “psycho-oncology” was being recognized in literature and practice settings such as Memorial Sloan-Kettering Cancer Center. Since the program’s inception, the LSA groups have grown steadily. (Fig 1).

Development of a Group

To assess the need for a group, chapters survey their local areas with regard to specific parameters (Table 1). Facilitators are recruited through the Oncology Nursing Society and the Association of Oncology Social Workers, as well as through chapter activities, board committees, press releases, flyers, and networking contacts. The potential candidate submits an application and a resume that are reviewed by the home office and approved by the advisory committee. Once approved, facilitators are invited to the Family Support Group Facilitators’ Conference, an annual training opportunity that is underwritten by the LSA. In the past two years, prominent speakers at the conference have discussed subjects such as group dynamics, co-leadership, grief and loss, the “difficult participant,” prescreening techniques, and updates on research for leukemia and oncology. The conference promotes structured learning and offers the opportunity for informal exchange among facilitators. The planning phase follows the preliminary needs assessment and the approval of facilitators. Group planning addresses the considerations presented in Table 2.

Co-leadership

Co-leadership is an important aspect of group work. The co-leadership policy allows group leaders to meet other commitments so one volunteer is not solely responsible for the outcome of the group. This stringent requirement of the program can be challenging since facilitators may come from different institutions and backgrounds and may employ various techniques that range from a systems approach to a more traditional medical model. This diverse but rich mix of volunteers is primarily composed of nurses and social workers, but also may include physicians, chaplains, psychologists, and educators.

Another advantage of co-leadership involves the rapport that can develop with more than one leader. According to Roller et al.11(p19) “since patients can identify with either or both therapists, co-therapy can enhance the patient’s ability to explore and reveal the many psychological parts of themselves.” In addition, sharing the workload via co-facilitation leads to greater logistic support and less anxiety for each facilitator.11(p24)

Groups meet at LSA chapters or in neighborhood locations. To avoid taking patients back to the “sights and smells” of distressing experiences, hospital meetings are discouraged. Technical assistance for all groups rests with the National Program Manager at the home office. Those with access to the Internet can find a group in the program through the LSA’s World Wide Web page (http://www.leukemia.org) by clicking on the map locator as shown in Fig 2.

Collaboration

The LSA has found that through collaborations, it can become more responsive to community needs as they arise. For example, a short-term group of eight to 10 weeks was formed in New York, NY, with Cancer Care, Inc, to assist leukemia, lymphoma, and myeloma patients who were struggling with returning to work and integrating their lives following bone marrow transplantation or chemotherapy. The collaboration enabled LSA to reach participants who were previously on a waiting list. The LSA also collaborates with organizations such as The Johns Hopkins Medical Cancer Center and the Wellness Community.

However, collaboration can create additional bureaucracies for the patient.12 For example, patients at one hospital may not be referred to groups offered at other hospitals, or they may be tacitly not welcomed.

On the other hand, institutional affiliation can be a useful prerequisite. It is increasingly common for social workers to appeal to different institutions for their endorsement of a group before starting a group. Initial endorsements can strongly influence the success or failure of a group. Also, it is important to maintain a core membership and a referral network. The network can receive updates about the group so that the referral sources don’t “dry up” from lack of information.8

Focus of Support Groups

Groups within the LSA vary in focus. Presently there are five pediatric groups, one cord blood pediatric group, one adolescent teleconference group, two bone marrow transplant groups, two parents’ groups, one short-term group, one group led with Spanish translation, and 63 additional groups for patients with leukemia, lymphoma, Hodgkin’s disease, and myeloma and their families and friends.

Five Stages of Group Development

Garland et al13 describe the five stages in the development of a group as preaffiliation, power and control, intimacy, differentiation, and separation. They suggest that the separation phase may be especially difficult in open-ended groups. Groups may suffer for various reasons: a lack of new ideas, resistance to ending the group, lagging of the program in which activities need to change, or the continuation of a group that should have ended.13 The constant flow of new patients into the groups, however,
mitigates the slow times by keeping the group responsive to change and using "veteran" members as "lay facilitators." In short, groups tend to move irregularly rather than uniformly on all relevant dimensions of group structure and process. Occasionally, members are unable to maintain a stable membership. When a group member dies, there is a sense of loss for which there may be no remedy but to take a break. This can be painful for co-facilitators. Performing a ritual (eg, lighting a candle, sending a flower) to acknowledge the "disenfranchised grief" is helpful. Disenfranchised grief is the mourning for losses that may not be mentioned in today's society (eg, a miscarriage or the death of a lover, pet, mentor, or the "person" one was in a healthier time). Groups that have shared scrapbooks, outings, diaries, and letters to a deceased loved one, when appropriate, are highly cohesive and have a strong core membership with flexible, nurturing facilitators.

The principle that participants must "move on" is a part of group development that a skilled leader will recognize. Patient support groups have a particularly intense ebb and flow as patients recover or at times become critically ill. For this reason, support groups for seriously illnesses sometimes appear to frighten potential members who quickly screen themselves out of the group experience. Participants report that it is too depressing, especially in the beginning phases. However, according to Mayo,6 confronting genuine tragedy is a highly cathartic experience psychically. Tragedy is inseparably connected with the human being's dignity and grandeur and is the accomplishment, as illustrated in the dramas of Oedipus and Orestes and Hamlet and Macbeth, of the person's moments of greatest insight.6

Similarly, Macy5 points out that "the first step in despair work is to disabuse ourselves of the notion that grief for our world is morbid. To experience anguish and anxiety in the face of the perils that threaten us is a healthy reaction. Far from being crazy, this pain is a testimony to the unity of life, the deep inner connections that relate us to all beings."

Participation in any type of counseling can help to satisfy the feeling that one can remain in control of one's mind if not one's body. Pollin et al18 state that "although support groups sound like the best of all possible solutions, they should not in and of themselves become a permanent way of life." They note that participating in such groups does not replace the need for acceptance in the larger society. These groups offer positive experiences for vulnerable patients, but at some point participants must leave the group and return to their previous lives.18

Integration

The key to any group at LSA is integration with other chapter activities. In the Central Connecticut chapter, for example, the board members send Christmas cards to the participants and visit the group each year. The group in Fairfield, Connecticut, was initiated through a public patient-education forum in which the speaker was a well-known oncologist and LSA board member. In the Rhode Island chapter, a monthly newsletter explains the range of patient services and fundraising activities. In the Northern California chapter, facilitators serve as resources for questions that come to the chapter from the field. Moreover, the local Patient Services Manager checks with each group after meetings to understand the content and processes that are at issue. Patients serve as spokespersons for the LSA at the annual radiothon. This supports the idea noted by Brager et al12 that the community worker's interest in the development of reciprocity among group members is fostered through interacting with members, being sensitive to their needs and feelings, identifying their commonalities, encouraging them to discuss their fears and hopes, and establishing bonds of trust among members. In this way, a common purpose and a desire to work together are forged. The establishment of affective relationships are in themselves important benefits that individuals derive from group participation, but from the community work perspective, a more important result is that these relationships may constitute an important collective resource to sustain a group through difficult times.12

Program Evaluation

Evaluation of the group program has been favorable. More than 600 patients were included in LSA's family support groups in the past year. Evaluative questions about LSA's groups consist of scaled responses to the quality of invited speakers, the length of the meetings, the opportunity to talk, the format of meetings, etc. Questionnaires request information on diagnosis, history, and demographics. Also, a section on group content and process asks members to rate the quality of their experience were met.

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Future evaluation questions might include the following: Does the group share a common philosophy? Do the members recommend that others attend? Can members articulate the purpose of the group? Is there any evidence of therapeutic factors in the group? The evaluation process will require additional attention to patient or family outcomes so the efficacy of patient support groups can be substantiated to donors, auditors, and health care organizations.

Adjuvant Approaches

A variety of other mechanisms that provide information and education for patients and their families have been developed. Several Internet sites have emerged to provide patients with the latest information or support available. Some of these sites are:

1. nationally recognized health care institutions such as the National Institutes of Health and the National Cancer Institute (http://www.nci.nih.gov) and the Physician Data Query (PDQ) (http://cancerdata.ncri.nih.gov/pdq.htm), Healthgate for abstracts and articles (http://www.healthgate.com), university sites for specific referral or protocol information such as the University of Pennsylvania's Oncolink cancer site (http://cancer.med.upenn.edu), sites of nonprofit organizations such as the Blood & Marrow Transplant Newsletter (http://www.bmtnews.org), or NOAH (New York Online Access to Health) for multilingual health materials (http://www.noah.cuny.edu)
2. newsgroups that assemble patients worldwide to share relevant information
3. chatgroup sessions among patients who access the Internet in real time (http://www.mania.apple.com)
4. commercial sites (eg, http://www.mediconsult.com) that offer information to consumers
5. medical journals available online (eg, Cancer Control at http://www.moffitt.usf.edu/pubs/ccj)
6. online and telephone support groups with professional moderators

A lack of professional moderators for chatgroups and newsgroups provides little quality assurance and allows misinformation. Nevertheless, patients in isolation waiting for marrow transplantations have provided ample testimony that being "connected" has been an invaluable tool. A teenager treated for Hodgkin's disease recently reported that she was able to attend school electronically. "The Group Room," an innovative broadcast radio show for cancer patients that is moderated by a professional social worker, takes calls from across the United States. Related organizations also arrange groups for patients and families (eg, Candlelighters for parents and their children, Chemocare for those undergoing chemotherapy, Cancer Care's 1-800-813-HOPE counseling line, and the International Myeloma Foundation).
In response to the need for services, especially when a patient is confronted with a diagnosis, the LSA has recently launched its "First Connection" program. Volunteers who have experienced leukemia, lymphoma, or myeloma -- either as former patients or through family members -- act as liaisons and resources for the program. They also provide peer counseling to patients who are beginning treatment for their disease. To date, more than 75 matches have been made in six chapters, and an additional 12 chapters will launch the program this year. The First Connection program uses the Family Support Group of the chapter to communicate with its participants, to train volunteers, and to provide a window into the community. It is an especially useful service for those not interested in groups or not yet ready to participate.

"Survivorship" is both the goal and the challenge of the new millennium. With the National Coalition of Cancer Survivorship housed within the NCI, a public acknowledgment of the continued problems of patients with cancer and leukemia has been made. To cope with various ongoing struggles such as relating to one's doctor and coping with a depressed immune system, loss of hair, bone pain, managed care and sexuality issues, opportunities for patients to talk about some of their more hidden feelings must be offered so they may achieve a quality of life free of extra anxieties. As long as there are stigmas and un-met needs associated with the illness, cancer support groups will multiply and, in many cases, become permanent components of cancer care. As a patient said of her two remissions, two relapses, and marrow transplant for acute myelogenous leukemia, "It's like I went to another planet for a few years, and now I'm back and I don't even know what hit me. Where do I begin?" We need to foster opportunities for meaningful outreach and meet each other somewhere between that "planet" and "here."

Conclusions

The longevity and continued growth of the leukemia support group program over the past 12 years support its continuing relevance. To further enhance the program, new concepts are needed to address the needs of children and teenagers. In addition, new research in pain management, and complementary therapies such as visualization, meditation, and massage should be addressed. Group facilitators want more exposure to such concepts and methods. While complementary therapies cannot substitute for the intensive, time-tested research of clinical scientists and practitioners, a group may be visited by a nutritionist or herbalist for recommendations on diet and lifestyle stressors. Finally, electronic media, the Internet, and teleconferencing will eliminate geographical and physical barriers to mutual aid. The strength of these groups is in their elasticity relative to community and medical care changes.

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References