

## The Evolution of a Cancer Support Center: A Work in Progress

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The diagnosis of cancer causes a significant level of psychosocial distress for patients and their families. Since the 1970s, researchers have documented the sources of distress and the emotional responses to illness along the continuum of care from diagnosis through treatment (Kornblith et al., 1992). Responses can range from mild distress to debilitating anxiety or depression (Christ, 1993; Zabora et al., 1997).

The National Comprehensive Cancer Network (NCCN) (2000) developed standards of care for the management of emotional, psychological, social, and spiritual distress in patients with cancer. Interventions may include individual counseling, group counseling (Cella & Yellen, 1993), family counseling (Abrams, 1974), and instruction on diagnosis, treatment strategies, side effects, and coping techniques. Research findings are combined with individual and family assessments to develop evidence-based interventions to help patients and their family members navigate through the cancer experience.

In the early 1990s, a group of patients with cancer, volunteers, and hospital staff at Athens Regional Medical Center (ARMC) in Georgia formed an advocacy group to explore the idea of a cancer support center. The goal was to create, at the institutional level, a process for providing emotional and treatment support.

In 1995, the group met with representatives from the ARMC administration and presented evidence that no centralized source of information existed for patients with cancer, their families, and healthcare staff. During that meeting and subsequent group discussions, patients reported that treatment and support efforts were fragmented. Numerous support services were available, but the community had no centralized source of information about treatment, care, and support. Focus groups with oncology physicians and patients were held separately to gain insights into perceived gaps in services. As proposed by Smith, Scammon, and Beck (1995), the information was used for program development and to support recommendations made by the advocacy group.

The advocacy group recommended that a single program and community center be established to facilitate the needs of patients and their families. Needs included support for psychosocial adjustment to the diagnosis and treatment of cancer, education for the management of disease and treatment side effects, and community education and screening programs. The goal was to provide these services free of charge for people diagnosed with cancer in the 17-county service area of ARMC. The efforts evolved to become the Loran Smith Center for Cancer Support, hereafter referred to as the center.

Funding for the center came directly from the community through the Athens Regional Foundation. ARMC financed the center's operation for two years until fund-raising goals were met. In 1998, a program manager was named and the vision, mission, and goal statements of the center were developed. During the following several months, an oncology nurse, who also was a survivor of cancer, and an office manager were hired.

On August 31, 2000, the center was dedicated. The Athens Regional Foundation had raised more than \$2 million from donations by ARMC employees, the ARMC auxiliary, and individuals and corporations in the community.

### Program Development

The program manager and oncology nurse developed the center's programs guided by the vision, mission, and goal statements. The goals were to

- Provide accurate medical information.
- Provide financial guidance.
- Offer psychosocial counseling across the cancer continuum.
- Establish support groups.
- Educate the community about prevention and early detection.
- Offer bereavement care.
- Educate patients and families to help manage disease and treatment side effects.

The program manager and oncology nurse had more than 20 cumulative years of clinical practice experience in oncology settings. The program manager had more than 12 years of

oncology social work experience in the inpatient setting. She was responsible for developing and guiding support services. The oncology nurse had 29 years of nursing experience, including 11 years in oncology nursing. She also had personal experience as a 14-year survivor of cancer. Several strategies were used to provide direction for the program, including site visits, an outside consultant specializing in the development of cancer centers, focus groups, and telephone surveys with patients.

Patient services began with inpatient visits, support group sessions, and educational seminars. In addition, miniretreats were offered to professional caregivers. These programs focused on ways professionals could manage the stress of their work and memorialize deceased patients. A tumor registry was started and managed through the Cancer Support Services Program. Two interns with master's degrees in social work were placed in oncologists' offices to ensure continuity of financial resources and emotional support among ARMC, the center, and physicians' offices. The interns were strategic referral sources to the center's services and were supervised by the licensed clinical social worker who also served as program manager.

Healthcare professionals should be available to patients and family members during times of potential crisis to assess for maladaptive behavior and assist them as needed (Van Fleet, 1998). The center's staff observed that patients and family members most often needed educational, psychosocial, or spiritual support during times of crisis; such periods were designated as touch points. Touch points occurred most often at diagnosis, during periods of treatment and symptom management, at recurrence, with a change in status from

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chronic to terminal illness, and during bereavement. This information was used during program development to budget resources, further refine psychoeducational services, and prioritize staff time.

### Informing the Community

Early fund-raising activity provided some publicity for the center. At the time the center was dedicated, its services still were largely unknown to people in the area. Brochures, advertisements, and oral presentations were prepared for community outreach activities to explain the services provided by the center. The information was designed to be interesting, informative, and concise and was directed toward different stakeholders, including patients, family members, and professional staff of hospitals, hospices, and physicians' offices. The staff at the center established trust among professionals and consumers to facilitate optimal and comforting patient care and support. They did so by being consistent, available, accurate, and competent (Bennis & Goldsmith, 1997).

An action plan was developed to provide hope and courage through support and information. Strategies for the plan aligned with the center's goals and included

- Continuation of the general support group and development of additional support groups for breast cancer, recurrent cancer, after treatment, and the grieving process
- Individual and family counseling
- Community education and cancer awareness programs
- Workshops in which community healthcare providers presented information about complementary therapies
- Assistance to staff in physicians' offices to provide specific cancer-screening and other services for professional caregivers and the community.

### Implementing the Action Plan

Collaboration among stakeholders was an important first step (Bennis & Goldsmith, 1997). The oncology nurse visited physicians' offices and met with office staff to explain current and developing programs, determine procedures for patient referral to the center, and uncover concerns for patient care. These early efforts opened lines of communication among the center, physicians, and their staffs. Mass media communication, including articles and advertisements in newsletters and local newspapers, also were used to reach a wide public audience.

### Social Work and Nursing Collaboration

A collaborative effort between the program manager and oncology nurse optimized the development of the center's educational and treatment services. Their experience and training were used in a complementary fashion to develop, prioritize, institute, and evaluate varying areas of program services. Indeed, a major strength of the center came

from the teamwork that developed between the program manager and oncology nurse. Both were available for inpatient visits, telephone consultations, appointments, and community speaking engagements. Close collaboration ensured prompt response to the needs of patients and their families. Although teamwork was a hallmark of the center, each member had a unique set of responsibilities. The oncology nurse was responsible for programs regarding symptom management, cancer awareness, and early detection and for support of patients during treatment. She developed support services for women undergoing diagnostic procedures and treatment for breast cancer and acted as a liaison among hospital departments, physicians' offices, and the center. The program manager's responsibilities included guiding program development to American College of Surgeons approval, overseeing the tumor registry, developing grief programs, providing programs about complementary therapy, and facilitating support groups.

### Problem Solving and Performance Improvement

An initial obstacle to the center's development was a lack of funding. This was addressed when the ARMC administration decided to provide startup money for two years to pay for employee salaries, educational materials, educational conferences, and administrative support. Later, the Athens Regional Foundation solicited donations from public and private donors. The ARMC auxiliary and hospital employee GIFT (Getting Involved For Tomorrow) program helped to meet the initial fund-raising goal. Additional funding was secured from pharmaceutical companies to support workshops, seminars, and classes.

Other obstacles were lack of community awareness of the center's services, physician and hospital staff reticence to make referrals (or inform patients about how they could self-refer), and competing demands on the time of the center's staff members. Lack of public awareness and reluctance to make referrals to the center were addressed in several ways. Staff members made presentations at meetings of the Athens Regional Foundation, community civic organizations, and ARMC staff meetings. They met with physicians and their office staffs to explain the center's purposes and programs. Newspaper and newsletter articles, as well as exhibits at community health fairs, raised community awareness. The staff at the center explored every opportunity to build relationships in the community.

Physicians were invited to participate in panel discussions about breast cancer awareness and present educational seminars about relevant cancer topics. The ongoing process of interaction among center staff, hospital personnel, and physicians fostered a sense of community, trust, and mutual support and has

increased the number of patient referrals to the center by physicians and ARMC.

The center's staff has addressed competing demands on time in several innovative ways. Staff hours are flexible to allow for late evening and weekend programs. Graduate students of social work, undergraduate and graduate students of health education, and undergraduate students of nursing have been recruited to assist in activities and programs as a vital component of their practicums. The center also recruits volunteers who are survivors of cancer, have a family history of cancer, or have strong interest in working with patients with cancer. The volunteers attend training sessions sponsored by ARMC and the center. Some work at health fair information booths, and others perform clerical duties and assist visitors in their use of center facilities and resources. Some volunteers are professionals who donate time to facilitate support groups or present programs about complementary therapies. One group of breast cancer survivors has volunteered to visit patients recovering from breast cancer surgery at the time of hospital discharge. Each patient is given a gift bag containing surgeon-approved breast cancer information, an axillary pillow, and a temporary breast prosthesis. The volunteers meet monthly to support each other, receive new information, and share their experiences. They are a valuable adjunct to the center's staff.

### Current Programs

The current operating hours of the center are 8 am–5 pm Mondays through Fridays, with additional hours for evening meetings. Some special activities include

- Workshops for healing grief, complementary therapy education, and gentle yoga for breast cancer patients
- Classes that address fatigue, pain management, and nutritional concerns brought about by cancer and its treatment
- Access to the quarterly American Cancer Society program "Look Good, Feel Better"
- Classes in creating scrapbooks and quilting that promote healing through storytelling.

The center also mails a monthly newsletter of upcoming events, motivational thoughts, educational opportunities outside of the center, and formal recognition of people for their contributions.

### A Work in Progress

The support provided by the center will change with the evolving needs of patients, families, and staff. When additional support groups or classes are needed, the center's staff will seek input from volunteers, support group members, and a leadership committee composed of center staff members, ARMC oncology inpatient unit staff members, and staff members from the offices of the medical and radiation oncologists. The center's staff members also have weekly evaluation meetings to review and amend current programs and prioritize the development of future programs.

Since its inception, the center has become a useful and effective adjunct to cancer care and support available in northeast Georgia. The staff at the center look forward to expanding its role within the community and fulfilling its mission to provide information, education, and counseling support to patients with cancer and their families. The main goals are to respond to the needs of the community by providing quality, comprehensive cancer care and to improve the health, wellness, and quality of life of members of the community. The Loran Smith Center for Cancer Support is the realization of the commitment of the Athens and northeast Georgia community to care for its neighbors affected by cancer, and the authors are proud of their role in this achievement.

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