

## 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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Digital Object Identifier: 10.1188/02.ONF.1397-1399