Expansion of an Outpatient Education Program in a Comprehensive Cancer Center

Nancy S. Kuhrik, MSN, PhD, RN, Marilee Kuhrik, MSN, PhD, RN, Eileen McCarthy, MSN, RN, and Maria Grabowski, MSN, RN

Information and educational interventions for patients with cancer and their families are ubiquitous in a comprehensive cancer center. Coping with the diagnosis and treatment of cancer is stressful and requires patients to learn how to manage the physical and emotional aspects of their care. Although needs vary across the cancer trajectory (Adams, 1991; Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004), patients with cancer, regardless of their age (Cassileth, Zupkis, Sutton-Smith, & March, 1980; Chelf et al., 2001, 2002), want as much information as possible to help them make treatment decisions (Chelf et al., 2001, 2002; Skalla et al., 2004).

Educators of patients with cancer and their families need to be cognizant of the particular challenge of cancer raising the specter of death; it can be a possible learning barrier but, on the positive side, a motivational factor to learn what is necessary to live (Agre & Shaftic, 2007). Providing a variety of methods for patients to learn about their disease processes and ways to handle side effects from medications and treatments allows patients to build a plan related to acquiring new material. Hearing information multiple times also helps learners develop schemata for complex information related to their cancer care. Teaching patients with cancer about their disease, how to manage treatment-related side effects, and strategies to improve quality of life has the potential to decrease patient anxiety and improve the cancer experience for patients and their families (Chelf et al., 2002). Skalla et al. (2004) reported that patients found it helpful to hear other patients share their experiences about management of their treatment-related side effects.

Background

The National Cancer Act of 1971 authorized the National Cancer Institute (NCI) to support a network of cancer centers that would be national leaders in cancer treatment, research, and education. The 2005 designation of the Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine in St. Louis, MO, as an NCI comprehensive cancer center prompted the executive director to focus on measures to improve visibility and accessibility of its existing patient education program to better serve patients.

Concurrent with the designation as an NCI comprehensive cancer center, patient educators were challenged to coordinate the expansion and enhancement of patient education throughout Siteman Cancer Center and began active participation in the Cancer Patient Education Network (CPEN). CPEN works in collaboration with NCI’s Office of Education and Special Initiatives and consists of a group of dedicated healthcare professionals throughout the United States and Canada, whose mission is to promote and provide models of excellence in patient, family, and community education across the continuum of care (www.cancerpatienteducation.org).

Implementation of a quality educational program in a hectic comprehensive cancer center is an enormous challenge. Chelf et al. (2002) suggested that if a cancer care team believes that support activities and education sessions have potential to improve the quality of life for patients with cancer, the care team should provide such comprehensive patient education programs and encourage patients to attend. Challenges for the development of an expanded patient education program are increasingly more complex in a busy comprehensive cancer center located within a large medical center to which some patients may travel more than 240 miles and present with diverse cancer diagnoses to receive complicated courses of treatment. The Siteman Cancer Center provides care for more than 7,000 newly diagnosed adult patients with cancer each year, with 250–300 outpatient visits daily for medical oncology treatments or appointments with oncologists or bone marrow transplantation physicians, as well as more than 32,000 follow-up visits annually.

Over the years, outpatient oncology education programs have been cosponsored by the Siteman Cancer Center, local nonprofit organizations, and pharmaceutical companies. In an attempt to meet the needs of all patients, programs were offered onsite, offsite, at different times of the day, and weekdays and weekends. Attendance at the programs was inconsistent, was limited, and reflected the unwillingness of patients and caregivers to return to the cancer center and other off-campus sites after they left the center. Regularly scheduled and special one-time onsite outpatient education programs provided while patients were present in the cancer center attracted minimal attendees when patients and caregivers were required to leave the immediate waiting area. Reasons for not attending generally were attributed to fear of missing appointments and the presence of treatment-related side effects (e.g., fatigue, nausea, pain).

In this article, the authors describe the process used and the challenges experienced when expanding and enhancing the patient education program in the cancer center using CPEN’s Guidelines for Establishing Comprehensive Cancer Patient Education Services (hereafter referred to as the guidelines). The guidelines are designed to serve as a model to help cancer centers, hospitals, clinics, and teaching institutions develop and improve the delivery, management, and quality of their education services for patients with cancer. The guidelines were developed by leaders from NCI-designated cancer centers to promote excellence in patient education as an integral component of the care of patients with cancer. The guidelines are intended to assist healthcare providers—especially educators—with their program planning, development, and evaluation responsibilities. Although