Expansion of an Outpatient Education Program in a Comprehensive Cancer Center

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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, Asles, & 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 & Shafic, 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 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
the guidelines were developed by and for representatives of NCI-designated cancer centers, they may be adapted for use by any group or organization concerned with cancer patient education (NCI Office of Cancer Information, Communication, and Education, 1999).

Plans to Enhance Patient Education

The objectives for this effort were to develop, implement, evaluate, and sustain a revised comprehensive oncology patient education curriculum that addressed treatment-related side effects and other topics that burden patients with cancer and caregivers. A proposal was presented and enthusiastically accepted by the director of oncology services to support the expanded educational program presented in the waiting rooms. The revised program would continue to support and reinforce the individualized teaching provided by oncologists, nurses, and other members of the oncology multidisciplinary team. A team of multidisciplinary healthcare providers was convened to establish a Patient Education Committee to discuss the process of enhancing the existing educational program using the guidelines. Mission and vision statements were developed to reflect the value of patient education at the Siteman Cancer Center and were congruent with the mission of Barnes-Jewish Hospital. The mission of the Siteman Cancer Center Patient Education Program is to provide patients, their caregivers, and the community with educational information to prevent, detect, and manage illness throughout the continuum of care. The vision is to be recognized as a national leader in comprehensive multimodality cancer education for patients, caregivers, and the community.

Curriculum Development

An ad hoc group of the committee identified core curricular threads and key topics (see Figure 1) to meet the complex needs of patients with cancer. The objective was to identify competent staff to implement an organized schedule of programs, services, and activities and to identify staff from various disciplines who could serve as multidisciplinary content experts. Instructional staff had to be comfortable presenting to small and large groups. The committee collaboratively developed specific measurable behavioral learning objectives for each program. As new topics were identified and requested by patients, additional content experts were recruited for presentations. A large pool of multidisciplinary speakers evolved; as the program became more successful, additional speakers stepped forward to share their expertise. Committee members discussed how presentations could be tailored to meet the needs of different patient populations receiving treatment (e.g., radiation oncology [Rad Onc], medical oncology [Med Onc], gynecologic oncology [Gyn Onc]) in the cancer center and address how patients’ needs may change during specific times and seasons throughout the year. For instance, during holiday seasons, the dietitian includes information related to holiday food and nutrition and the oncology psychologist discusses how to handle additional stress associated with having cancer and receiving treatment during holiday seasons. Some presentations are geared toward caregivers. Per patients’ requests, attention was given to educational materials about cancers recognized during designated awareness months. Because the education programs were designed specifically for patients at the Siteman Cancer Center, the committee chose the name SEP, an acronym for Siteman Education Program.

Pilot Implementation

Because patients were hesitant to leave waiting areas to attend educational programs, the committee decided to pilot programs where the learning opportunities would be “taken to patients in high-traffic areas” to reach those who were coming and going for treatments and physician appointments. Pilot presentations were held in waiting rooms of an outpatient Med Onc area, two inpatient units, Rad Onc, and the Gyn Onc infusion center. The sessions covered many topics and welcomed patients, families, and caregivers. The same format, topics, and content experts were used in each area. Nurse managers and designated patient education nurses from each unit informed patients, family members, and visitors about upcoming sessions in their waiting areas.

After approximately six months, the committee agreed that the pilot was successful in all of the outpatient areas; however, lack of success in the two inpatient units was attributed to the severely ill conditions of patients and the inability of family members and caregivers to leave patient rooms to attend the sessions. Therefore, the committee continued to focus only on outpatient areas.

Successful Implementation

Although pilot sessions were successful in all outpatient areas, modification and creative strategies were necessary to promote and sustain ongoing success in each unique outpatient setting that addressed or considered the size of the environment and volume of patients (see Table 1). For example, the large Med Onc waiting room has 250–300 visits daily; because of its vast size, speakers need a microphone and podium. On the other hand, the smaller Gyn Onc infusion center has a more intimate atmosphere, and the speaker often is seated at a large, round table with the patients and caregivers. In the waiting rooms of Med Onc and Rad Onc, patients participate in the program either before or after their appointments; in Gyn Onc, patients are assisted to walk out of their treatment rooms to the round table and actively receive treatment while RNs closely monitor chemotherapy and attend to patient needs. Seminal research by Corney, Everett, Howells, and Crowther (1992) and Chelf et al. (2002) reported that women who had gynecologic cancer wanted more information about their surgery and treatment and preferred their husbands be present with them during such discussions. The authors of the current article have found this to be true during presentations on the Gyn...
Onc infusion unit; husbands and other supportive family members usually join patients at the table to listen. During all sessions, speakers maintain an informal format and encourage group interaction and participation. Speakers with less experience have found that educational content can be condensed and, therefore, modified their content for future presentations. Other speakers have become more comfortable over time and allow patients and caregivers to interject personal experiences and stories.

The committee was very cognizant of health literacy issues and the need for health professionals to provide all educational material in a way that individuals can obtain, process, and understand basic health information and make appropriate health decisions. Therefore, speakers are encouraged to use non-medical, patient-friendly language so they are understood easily. Attention is given to ensure that all educational materials meet approved cancer center health literacy guidelines (not to exceed the sixth-grade reading level).

A description of session locations and times are on the electronic calendar, which is posted on the cancer center’s Web site (www.siteman.wustl.edu), and 650 hard copies are distributed widely to all oncology patient care areas and throughout the medical center. Colorful descriptive flyers and posters, designed by the marketing department, advertise and promote the sessions. The posters were crafted with a clear plastic sleeve to hold an interchangeable flyer detailing the upcoming topic and speaker. This was a result of attendees’ requests that more information about upcoming speakers and topics be advertised so that patients could make plans to attend programs of interest.

### Facilitation and Introduction

Each session is introduced to the audience by a facilitator who is a master’s-prepared RN with oncology expertise. Before the program begins, the facilitator welcomes attendees and announces that an educational program will be taking place in a designated area of the waiting room. At that time, patients who do not want to participate, do not want to listen to the topic, or prefer quiet time have the opportunity to move to a different area. A problem occurred when receptionists called out patients’ names in the waiting room while the presenter was speaking; this distraction was alleviated with the implementation of a beeper system. The facilitator also invites participants to enjoy complimentary snacks and a chair massage, offered monthly in each area.

When choosing menu items, planners are sensitive to patient requests and specific nutritional needs of patients receiving chemotherapy (i.e., softer, bland foods versus spicy foods). To role model infection-control standards, hand foam is provided for patient use and all beverage and food items are individually packaged. Topic-specific national publications, Microsoft® PowerPoint® handouts, and supportive material such as word searches and crossword puzzles are distributed. Costs for food, massage, and educational materials are covered through funding by a Barnes-Jewish Hospital Foundation Grant and a Dula Foundation Grant that support patient education and support services; therefore, sessions are free for participants.

### Evaluation

Overall, feedback has been overwhelmingly positive, with attendees commenting on the value of the sessions. Some examples of comments provided by attendees regarding what they liked most about the programs included, “Thank you—It’s like you knew what I needed to know,” “Just the fact that it is available for patients while they wait.
and it is also informative.” “Thank you for continuing to find ways to educate and support a person living with cancer,” “Thank you—I really enjoyed it, while waiting. I found this to be a good break in the waiting room activities or lack thereof,” “It touched on serious points in a short time—convenient to us in clinic,” and “Just keep doing and keep giving encouragement for the patient and caregivers.” Suggestions for improvement have included having the presenters speak more loudly, using a better microphone, distributing more handouts, covering different topics, having more programs, and changing food options. Input also is garnered from multidisciplinary members of the Siteman Cancer Center Professional Advisory Council.

Discussion

The sessions were adapted to maximize patient participation in the cancer center. By providing educational sessions when patients are waiting for treatments and appointments, the program has taken advantage of the “teachable moment.” Speakers and facilitators adjusted to each unique setting, where interruptions are common and expected. Since accurate attendance counts began in 2004, more than 9,608 patients and caregivers have attended the onsite education programs. The success of the program is evident by the positive evaluations and the numbers of participants who have chosen to attend throughout the years. The guidelines have been a helpful model as the center continually strives to improve the sessions. The recommendations for designing such a program are as follows.

- Start slow and garner administrative staff and patient support.
- Once the program becomes a “regular attraction,” patient and staff look forward to it and plan accordingly.

Future Plans

Because the success of the sessions depends on the steady flow of speakers who voluntarily come forward, the committee is seeking ways to recognize their contributions publicly. At this time, thoughts include printing certificates with speakers’ names or hosting a breakfast or luncheon to honor the speakers. The committee continues to work on improving dates, times, and locations of offerings so as not to conflict with other cancer center events occurring at the same time. Strategic scheduling is essential; sessions must be varied in relation to time and setting to accommodate scheduling challenges and provide the greatest access to patients.

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Leadership & Professional Development

This feature provides a platform for oncology nurses to illustrate the many ways that leadership may be realized and professional practice may transform cancer care. Possible submissions include, but are not limited to, overviews of projects, accounts of the application of leadership principles or theories to practice, and interviews with nurse leaders. Descriptions of activities, projects, or action plans that are ongoing or completed are welcome. Manuscripts should clearly link the content to the impact on cancer care. Manuscripts should be six to eight double-spaced pages, exclusive of references and tables, and accompanied by a cover letter requesting consideration for this feature. For more information, contact Associate Editor Mary Ellen Smith Glasgow, PhD, RN, CS, at Maryellen.smith.glascow@drexel.edu or Associate Editor Judith K. Payne, PhD, RN, AOCN®, at payne031@mc.duke.edu.