

## Abstract

Recent trends in health care have placed increased burden on family caregivers. In response, a psychoeducational program for cancer caregivers has been implemented. This 6-hour program addresses symptom management, psychosocial support, and resource identification. Between 1994 and 1997, 520 caregivers have participated. The majority have been married women that were in the caregiving role for at least 3 months. Despite multiple demands reported by caregivers, psychosocial issues, such as watching the patient become more ill and not knowing what to do, are reported as the most difficult aspects of the caregiving role. The supportive group setting is an ideal forum to address these issues.

## Key Words

cancer trajectory  
caregiver burden  
caregivers  
psychoeducational  
program  
quality of life

# Enhancing Quality of Life of Cancer Caregivers Through the Use of a Family Caregiver Cancer Education Program

JEANNIE V. PASACRETA, PhD, RN, CS, AND FRANCES K. BARG, MED

Recent years have seen an escalating trend toward early discharge of hospitalized patients. As a result, patients with cancer are being cared for at home in increasing numbers and at different stages of disease by family members.<sup>1-5</sup> This demand on families is not new, although the family caregiver role has changed dramatically from promoting convalescence to providing high-technology care and psychological support in the home. Members of the patient's family are of vital importance in meeting the patient's physical and psychosocial needs and accomplishing treatment goals.<sup>6</sup> The burden of caring for patients with cancer may adversely affect families who lack adequate resources or who are insufficiently prepared for this new, complex role. There is mounting evidence that changes in family roles and the burden placed on family caregivers may have negative effects on the quality of life of both cancer patients and their caregivers.<sup>5</sup>

Quality of life is a multidimensional construct that, for the purposes of this discussion, encompasses subjective aspects of functioning and well-being and includes the patient and family as the unit of focus. Rapidly expanding technologies and new treatments have rendered previously intractable cancers manageable, but within the context of a range of side effects and toxicities. Thus, to varying degrees, these therapies may diminish the quality of life of those that they are "saving,"<sup>7</sup> as well as the quality of life of family members who have increasingly become primary care providers, often within the context of other demands. Ongoing research indicates that there is an acute need to describe the growing population of cancer caregivers and to address their complex needs for education and support.

Based on the preceding issues, funding for the development, implementation, and evaluation of a Family Caregiver Cancer Education Program (FCCEP) was

*Jeannie V. Pasacreta is Project Director and Coinvestigator, and Frances K. Barg is Principal Investigator, Family Caregiver and Cancer Education Program, University of Pennsylvania School of Nursing, Philadelphia.*



awarded by the Commonwealth of Pennsylvania to four contractors across the state. This paper describes the nature and success of the program and emphasizes the need for similar programs nationwide. A case study is presented to clarify important aspects of the FCCEP and their impact on quality of life issues. Because family caregivers are assuming increasing responsibility for the care of their loved ones with cancer, health care professionals should be informed of the factors that affect the quality of life of patients and caregivers, the needs of caregivers across the cancer trajectory, and the efficacy of various modes of intervention in minimizing distress and promoting quality of life. In addition to equating caregiver support with improved quality of life for the patient and caregiver, an important goal of this paper is to alert readers to some of the special challenges that professionals face when attempting to address caregiver needs, particularly in a changing health care environment. Specific efforts that have been undertaken to improve access to the FCCEP are highlighted, with the goal of promoting caregiver support programs as a standard of modern health care.

### **Purpose and Description of the FCCEP**

The purpose of the FCCEP is to prepare oncology nurse and social work teams to teach and support family members to care at home for their loved ones with cancer, and to develop a network of local resources to be available to meet caregiver needs in the community. The FCCEP is a psychoeducational program that focuses on the medical realities of cancer, such as symptom management, improvement of technical competence, and medication administration in the home. The FCCEP's content categories were identified by a panel of 20 multidisciplinary experts in oncology, who met over the course of several sessions to provide consultation regarding curriculum development to the FCCEP investigators. Important issues identified included such diverse areas as talking to a loved one's physician and dealing with other aspects of the health care system, handling role and relationship changes in the family, taking care of medical equipment, managing uncomfortable symptoms, talking to children, managing other jobs and responsibilities, handling insurance and financial issues, coping with the patient's and caregiver's emotional reactions, finding and asking for help, and managing self-care. Family members are given support for their feelings about caregiving and helped to negotiate a complex, often impersonal medical system. Common emotional reactions to caregiving are explained, such as anger, depression, and family role changes, which can have a negative impact on the quality of the caregiver's life. During instructor training sessions, nurse/social worker teams are taught to be alert to caregivers who might be at risk of developing problems with their new roles and to put those individuals in touch

with appropriate resources (psychotherapists and insurance consultants are two common examples).

Caregivers are invited to participate in the FCCEP during or following transition points in the patient's course of illness (eg, diagnosis, recurrence, initiation or cessation of treatment, shifts in treatment goals from curative to palliative treatment). The clinical course of cancer follows one of several trajectories that present specific challenges for patients and their families. A number of patients respond to the curative attempt with no recurrence of disease and are, after a period of time, considered cured. Some patients have a positive response to a curative attempt but then develop recurrence or metastasis. Other patients begin treatment with a hope for cure but do not respond and progressively decline. In some patients, the disease is too far advanced at diagnosis to even attempt a cure, and management of disease progression is strictly palliative.

The acute stress response has been described as the usual response occurring at each transitional point of illness (diagnosis of cancer, start of treatment, recurrence, treatment failure, disease progression).<sup>8,9</sup> The response is characterized by shock, disbelief, anxiety, depression, sleep and appetite disturbance, and difficulty performing activities of daily living. These symptoms are often present in patients and families and can interfere with critical thinking and problem solving.<sup>10</sup> The timing of the program is based on the rationale that transition points in the cancer trajectory are associated with increased vulnerability for the patient and family, requiring new skills and enhancement of effective coping strategies.<sup>9</sup>

### **Implementation of the Program**

Each FCCEP is 6 hours long and is taught over the course of one to three sessions. Recommended group size ranges from 5 to 16 members to maximize group process and dynamics.<sup>11</sup> Nurse/social worker teams participate in a 1-day intensive training prior to becoming FCCEP facilitators. Following training, they meet two to four times yearly as a group and have regular telephone contact with the program investigators.

Between April 1994 and March 1997, 520 caregivers participated in 58 family caregiver education programs. The majority of participants were female and married and were in the caregiving role for at least 3 months. Despite multiple physical, medical, and financial demands reported by caregivers, psychosocial issues, such as watching the patient become more ill and not knowing what to do, were reported as the most difficult aspects of the caregiving role. Ideally, these concerns were addressed in the support group setting. During the implementation phase of the program, many participating institutions had had layoffs, department reorganizations, and consolidation of positions. These institutional changes are indicative of dramatic changes in



health care delivery and financing that are occurring across the country. Two major consequences of the changes in health care to the FCCEP are the increased burden imposed on family caregivers because of accelerating trends of early hospital discharge and the increased burden placed on FCCEP instructor teams. Facilitators report having to assume greater responsibility and exposure to increasingly complex patient and family problems in their caseloads. As a result of these issues, the absolute importance of the FCCEP has been highlighted. It is also clear that programmatic support for facilitators is an essential and escalating need as trends in health care continue to dictate the realities of the workplace.

### **Contemporary Issues Facing Family Caregivers: A Case Study**

At a recent FCCEP session, a group of men and women sat in a circle and talked about the struggles they faced at home caring for loved ones with cancer. One woman's story was particularly poignant. John and Mary Smith, a middle-aged couple, were in their prime. The last of their four children had just moved out of the house, John had just retired, and the couple was ready to enjoy some travel and long-awaited time alone together. To their dismay, John developed acute leukemia, and, seemingly overnight, their lives turned into a maze filled with unfamiliar medical personnel, frightening and uncomfortable procedures and treatments, unbelievable medical bills, and emotion-filled days and nights. Following a 2-week hospitalization, John was sent home and was largely under Mary's care. John suffered from mood swings, mouth sores, and unending fatigue and also had an indwelling venous catheter that required regular maintenance. In addition to managing the burden of his physical and emotional care, Mary was forced to retain her secretarial job for the income and supplemental insurance it provided. The Smiths' four children were in college or managing families of their own and, although supportive, were unavailable to provide direct care or respite for Mary. After 2 weeks of ministering to his needs and juggling her other responsibilities, Mary felt overwhelmed and depressed. The help she received from family and friends was not enough. She felt angry, isolated, and alone and did not know where to turn.

It is clear in this case that the cancer experience can adversely affect the quality of life of the patient and family caregivers, who may lack adequate resources or who are insufficiently prepared for this new, complex role. On visit to the oncology clinic for a follow-up appointment, Mary noticed a flyer announcing an upcoming FCCEP session. Although she was reluctant to go at first, the social worker in charge of John's case convinced her that it could be a worthwhile experience. At the social worker's suggestion, Mary was able to ask one of her children to be available to John while she attended the course so that

she could devote her full attention to the program. The course was extremely helpful. Mary received concrete information about symptom management but, most important, was put in touch with a group of people who were experiencing problems similar to hers. Her feelings of anger and helplessness were validated, and she was finally given permission to ask for help and provided with specific resources to turn to.

The FCCEP has provided major assistance to caregivers like Mary Smith. Symptom management is taught to increase caregivers' proficiency and sense of competence in caring for the patient. Communication skills are taught to help caregivers get what they need from friends, other family members, and health care professionals. In addition, community resources are explicitly detailed, and caregivers are directed toward specific resources that pertain to their particular situations. Mobilizing caregivers' ability to ask for help and identify resources is a key component of the FCCEP and is precipitated by diminishing inpatient care and increasing home- and community-based care that are inherent in modern health care.

### **Changes in Health Care Delivery**

The period spanning the middle of the 20th century, during which patients were routinely cared for in acute care hospitals, may turn out to be only a brief period in medical history. Before this time, patients were cared for primarily at home by their families. Today, social and economic forces are interacting to remove patients from the hospital and return them home.<sup>12</sup> Although at face value this change seems positive, simultaneous changes among American health care consumers have highlighted large gaps and deficiencies in the health care delivery system. Dramatic advances in technology have allowed us to keep patients alive increasingly long despite complex and chronic health problems. The burden of their care usually falls on patients and families who are often not adequately prepared to handle the physically and emotionally demanding needs inherent in chronic health problems. Additionally, the need for members to work outside the home and alter work schedules when faced with a sick relative has created an as yet immeasurable strain on physical, emotional, and financial resources. Full appreciation regarding the impact of these issues on the quality of life of patients and caregivers remains to be seen.

Paradoxically, institutional changes are occurring at a time when the needs of caregivers are becoming more complex and burdensome to their own families, to the professionals that treat them, and to society at large. The experience of overseeing the implementation of the FCCEP has been valuable. The need for the education and support that the program offers to caregivers is clear and growing. In light of dramatic changes in health care delivery that are occurring throughout the country, however,



innovative strategies for disseminating information and support to caregivers and the professionals that assist them are critically needed so that the caregiver education can ultimately become a routine standard of care.

### **Improving Access to the FCCEP**

During the course of the development and implementation of the FCCEP, the contractors experimented with a variety of innovative ways to disseminate the information, support, and resources inherent in the program and promote its essence as a standard of care. Some of these attempts are described below.

#### ***Establishing a Presence on the Internet***

An Internet site devoted to the contents of the FCCEP has been placed in OncoLink, a cancer information and education service on the World Wide Web. OncoLink, which can be accessed at <http://www.oncolink.upenn.edu>, has developed into a major source of cancer information for patients, the public, and health care providers. This service, which began March 7, 1994, has the ability to track usage and reports over 1 million accesses each month. The FCCEP site ([http://www.oncolink.upenn.edu/upcc/fam\\_caregiver.html](http://www.oncolink.upenn.edu/upcc/fam_caregiver.html)) was visited 727 times in 1 month alone. The strength of this mode of dissemination includes reaching a large number of caregivers as well as individuals who are averse to a group setting. Obviously, one must have access to a computer, modem, and software, which eliminates a number of needy caregivers, but, nonetheless, response to this high-technology format has been noteworthy and is growing rapidly.

#### ***Offering the Program to Adolescents***

The FCCEP curriculum has recently been adapted to the needs and development of young adolescents, and it is soon to be offered at a pilot middle school. The adapted curriculum will be presented by a specially trained team of FCCEP instructors. Ultimately, this program may serve as a prototype for other schools, and the experience can serve as a testament of the program's benefits and potential for this age group. Personnel at the pilot school have commented on how prevalent cancer is among parents of many of the students and how helpful they think the FCCEP course will be. In cancer education programs at the school, students have expressed concerns and posed questions about their parents' cancer as well as their own personal risk.

#### ***Publicizing the Program to Corporations***

Contractors meet regularly with area corporations to inform them of the FCCEP, particularly of program meetings and schedules and/or to design special programs for specific work sites. The American Cancer Society's home-maker program has been used as a vehicle to promote

awareness of the program where the incidence of caregiving in the home is high.

#### ***Using Community Outreach Workers***

Based on some of the recruitment problems that the FCCEP experienced during its first year, a community outreach component was added to reach caregivers on their own ground. Community outreach workers promote access through churches and community centers. In addition, they market courses directly within specific and well-defined communities. The community outreach workers serve as a direct link between the FCCEP contractors and the community. They work as a team to promote community awareness and participation in the FCCEP. Outreach workers travel to health care institutions, community organizations, and meetings to perform case-finding duties and to provide information and referral for community resources for people with cancer and their families. They also assist project staff with data collection, marketing, and program development. In essence, they perform many functions that local instructors no longer have the time to perform and thus are responsible for the ongoing and successful implementation of the program during rapidly changing times.

#### ***Offering Respite Care***

One problem that was clearly a barrier to successful recruitment was the inability and/or unwillingness of caregivers to leave patients alone while they attended the FCCEP. We have successfully enlisted the support of home health agencies in providing free respite care to families so that they can attend. This source of support has proved extremely valuable. In return for this support, the agencies in essence gain exposure to a broad community of professionals and caregivers and lend support to a worthwhile, well-respected program. The use of respite services has also increased awareness of a group of homebound caregivers, who, for a variety of reasons, are unable to leave the home to attend groups in the community. Based on the needs of this group, FCCEP contractors are examining the feasibility of conducting telephone groups so that resources can be made available to homebound caregivers.

#### ***Holding Regular Meetings With Local Instructors***

At our first annual meeting, local instructors verbalized the importance of formal meetings with project staff. Instructors felt a need to obtain feedback about programs and to network with other FCCEP local instructors. Meetings are held biannually and are a great morale booster as well as a suitable forum for troubleshooting problems and brainstorming regarding key issues such as recruitment. At each meeting, data are presented regarding caregiver characteristics and updated findings



related to the FCCEP. A noted researcher and/or advocate in the area of caregiving is invited to speak to offer his or her perspective and advice regarding aspects of the program.

### Conclusions

Reports from caregivers at FCCEP meetings substantiate the profound impact of the cancer experience on the quality of life of patients and their family caregivers. Data collection before and after FCCEP attendance describes and quantifies these issues. Caregivers report that they experience extraordinary burden largely because there are inadequate resources to assist them. Current trends in health care reform focus on cutting costs in acute care settings, resulting in a drastic shift of care from the hospital to the home. Despite what seem to be societal cost savings and enhanced efficiency of the health care system, the locus of financial, physical, and emotional burden is shifting to families, who must often leave jobs, lose benefits, and imperil their own health. Ultimately these issues will strain our economy in new, presently undocumented ways. More initiatives that advocate for caregivers in these changing times are paramount. The importance of documenting caregiver responses to their situations and the impact of psychoeducational interventions, such as the FCCEP,

are also critical for such initiatives to have an impact on public policy.

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