The Living Well After Cancer Program: An Advanced Practice Model of Care

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In 1996, the National Cancer Institute (NCI) established the Office of Cancer Survivorship (OCS) to provide a focus within the National Institutes of Health for the support of research and education aimed at professionals who treat patients with cancer. In doing so, NCI recognized the large number of individuals who survive cancer and their unique concerns.

The OCS objectives are to
- Develop an agenda for the continuous acquisition of knowledge about problems facing survivors of cancer, including the medical, psychological, and economic late effects of treatment
- Support studies that aim to increase the length of survival for patients with cancer, including those that involve prevention of subsequent disease and disability
- Enable the dissemination of information to healthcare professionals concerning the problems and needs of survivors of cancer
- Assist in providing information to the public about the issues of concern to survivors of cancer
- Improve the quality of survival of all individuals diagnosed with cancer (Meadows et al., 1998).

In the fall of 2000, the University of Pennsylvania Cancer Center in Philadelphia received a two-year grant from the Lance Armstrong Foundation to develop a multidisciplinary program for adult survivors of cancer that would integrate clinical care, research, and education. OCS objectives guided the conceptualization of the Living Well After Cancer program and were the force behind the development of its clinical care, research, and education components. This program was modeled after the pediatric cancer survivor program at The Children’s Hospital of Philadelphia (CHOP) in Pennsylvania, and an oncology advanced practice nurse (APN) served as program coordinator.

Background

Cancer has become a chronic illness. For the most part, even patients who ultimately die of their disease live years past initial diagnosis. The first improvements in cure rates were made in pediatrics. In 1960, only 1% of children diagnosed with leukemia were alive five years after diagnosis (Keith & Brown, 1971). In the past 25 years, significant improvements have been made in the five-year relative survival rate of many childhood cancers, especially acute lymphocytic and acute myeloid leukemias, non-Hodgkin’s lymphoma, and Wilms tumor. For all cancer sites, the rate among children improved from 56% in 1974–1976 to 77% in 1992–1997 (Ries et al., 2001). Cancer survival rates for adults also have improved. Ries et al. predicted that, of the 203,500 women who will be diagnosed with breast cancer in 2002, 80% will survive at least five years. In addition, Ries et al. predicted that, of about 7,500 men to be diagnosed with testicular cancer in 2002, the overwhelming majority will be cured of their disease and also become long-term survivors.

The increases in survival rates are a result of many treatment advances (Meadows et al., 1998). However, these advances also contribute to deleterious physiologic and psychological effects called long-term or late effects of treatment, which may not arise until years after treatment has ended. Patients at greatest risk for developing late effects are the very young and the elderly. Damage caused by chemotherapy and radiation is most harmful in children because their multiorgan systems with rapidly dividing cells are most affected by cancer treatment. In adults, the process is different: Aging results in a decline of each organ that is influenced by an individual’s diet, personal habits, and genetic factors; therefore, the older the individual, the more organ decline he or she has sustained. This decline may be accelerated for survivors of cancer, depending on the type of cancer and treatment (Harpham, 1998). Consequently, children and the elderly are at higher risk for developing late effects of treatment than young and middle-aged adults.

The identification of late effects of treatment and the subsequent need for specialized focused care for children who survived cancer began more than 20 years ago (Schwartz, Constine, & Hobbie, 1994). In response to this need, Anna Meadows, MD, and Wendy L. Hobbie, MSN, CRNP, developed a follow-up program at CHOP in the early 1980s for childhood survivors of cancer. The program has served as a model for survivorship programs throughout North America, delineating the necessary components for a successful program, the specific roles of team members, and the specialized needs of long-term survivors of childhood cancer. The clinicians at CHOP found that a successful program must include a multidisciplinary team, institutional support, adequate time allotment for visits, and development and maintenance of a comprehensive database to track survivors and provide the basis for empirical studies (Harvey, Hobbie, Shaw, & Bottomley, 1999). Some identified roadblocks to care were healthcare insurance and institutional financial issues, as well as unwillingness of healthcare providers to refer patients to the program. Despite the success of this and many similar pediatric survivorship programs, the focus of care for adult survivors of childhood cancer has not had the necessary components for a successful program, the specific roles of team members, and the specialized needs of long-term survivors of childhood cancer. The clinicians at CHOP found that a successful program must include a multidisciplinary team, institutional support, adequate time allotment for visits, and development and maintenance of a comprehensive database to track survivors and provide the basis for empirical studies (Harvey, Hobbie, Shaw, & Bottomley, 1999). Some identified roadblocks to care were healthcare insurance and institutional financial issues, as well as unwillingness of healthcare providers to refer patients to the program. Despite the success of this and many similar pediatric survivorship programs, the focus of care for adult survivors of childhood cancer has not had the necessary components for a successful program, the specific roles of team members, and the specialized needs of long-term survivors of childhood cancer.