Identifying barriers to cancer survivorship programs

Successful implementation of survivorship programs can be impeded by institutional policies, physician attitudes, and patient perceptions.

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Advances in cancer screening have improved both early detection of the disease and treatment effectiveness. As a result, persons who would not have survived cancer may live many years after completing a prescribed plan of cancer treatment.[1] Nurses and other medical professionals should be both compelled and obligated to offer services that address the multifaceted long-term effects of the physical, emotional, and financial burden of cancer and its treatment as it affects patients beyond primary treatment.

The need for oncology nurses to be involved in investigating, identifying, and overcoming the barriers to successful cancer survivorship programs is increasingly evident by the emerging societal awareness of cancer survivorship issues. With the knowledge gained from focused research on these issues, nurses can be a catalytic force in eliminating barriers that limit active participation in survivorship programs. Currently, several models exist for structuring survivorship programs, including the Lance Armstrong Livestrong Foundation, the National Coalition for Cancer Survivorship (NCCS), and the National Cancer Institute (NCI) Office of Cancer Survivorship. These organizations offer frameworks for patient-focused interventions from which nursing can assimilate plans of care that address the unique needs of the cancer survivor.

DEMOGRAPHICS OF SURVIVORSHIP

The NCI Surveillance Epidemiology and End Results (SEER) report, *Cancer Statistics Review,* predicts approximately 40.77% of people born today will develop some type of cancer during their lifetime.[2] Furthermore, an estimated 66% of the approximately 11.7 million people living with a diagnosed cancer in the United States at the beginning of 2007 are expected to still be alive at least 5 years after their cancer diagnosis.[2] In a 2010 study, Mariotto and colleagues reported health care costs for approximately 13.8 million cancer survivors was estimated at $124.57 billion.[3] Their research concluded that current incidence and survival rates are expected to increase those estimates to 18.1 million cancer survivors at an annual cost of $157.77 billion by 2020.[3]

Patients who survive cancer beyond treatment often experience physical, social, emotional, financial, and spiritual changes as a direct result of their cancer diagnosis and treatment. Emerging post-cancer-treatment issues increase the need for nurses to understand how these changes relate to prevention of secondary disease, as well as a focus on patient health and efforts to prevent cancer recurrence. Patients' struggle with long-term effects of chemotherapy is potentially problematic over time. Delayed effects of chemotherapy often occur months and even years after treatment.

EVOLUTION OF SUPPORTIVE CARE

Support groups typically served as the traditional modality for addressing cancer-related care issues until the early 1990s. These groups promoted emotional support and helped patients cope with the fear of dying and disease recurrence; however, they did not address other aspects of ongoing post-cancer-treatment care.[4] The paradigm of studying and providing cumulative and ongoing survivorship care has emerged through public awareness and scholarly interest. Current attention from professional organizations such as the Oncology Nursing Society (ONS), the American Society of Clinical Oncologists (ASCO), and the American Cancer Society (ACS), combined with efforts by grass roots consumer organizations such as the NCCS, the Lance Armstrong Livestrong Foundation, and the Susan G. Komen for the Cure Foundation have increased public awareness and advocacy for more research of cogent and modern cancer survivorship issues.

Oncology as a specialty has evolved significantly in the last half century. Historically, educational materials on cancer and chemotherapy were not readily available, and formalized support programs were nonexistent. Cancer and survivorship advocacy has expanded to models of self-organizational and public policy advocacy.[5] The Office of Cancer Survivorship, created by the NCI in 1996, has continuously tasked investigators with research that would further define and improve quality of life issues for long-term cancer survivors.[6] Depression, cognitive difficulties, fatigue, aches and pains, insomnia, and decline in social function and interaction are identified as lasting and progressive effects long after the initial cancer diagnosis.[7]

Unrecognized barriers hinder the implementation of successful cancer survivorship programs. A survey of 399 active ONS members showed only 27% of respondents were employed in a setting that had a formal, structured cancer survivorship program.[8] The most significant barriers to survivorship care programs were a lack of funding and an inability to have designated clinical time allocated for cancer survivorship programs. In addition, clinical experience in oncology had an impact on knowledge of cancer survivorship. Forty-nine percent of respondents who had less than 5 years of experience in oncology reported a lack of sufficient knowledge about cancer survivorship compared with 36% of respondents who had more than 5 years of combined nursing oncology experience.[8]

Efforts should concentrate on identifying the variables that prohibit successful operation of community practice-based cancer survivorship programs, as well as the variables that might discourage patient enrollment and active participation. For example, many studies focus on survivorship concerns for pediatric patients with cancer; however, consistent guidelines for adult survivors of pediatric cancers are lacking.[9] This gap is not only a barrier to complete care for these patients, but also illustrates a wide practice gap between clinical research and applicable models for nursing care.

Identifying these barriers can provide insight for navigating beyond perceived obstacles, ultimately providing more survivors of cancer with the posttreatment care and support they need. Until survivorship research becomes applicable to real-time practice, nurses should document identified needs of cancer survivors. Nurses should assist patients by actively seeking out those programs, facilities, and organizations that provide specialized care for cancer survivors, and they should

TABLE 1. Supplementary roles for nurses[11]

Liaison and advocate for ensuring patients' unique needs are addressed
Primary care provider with a specialty in disease states, symptomology, and manifestations of illness caused by cancer care
Support team leader during and after cancer care

TABLE 2. Barriers to cancer survivorship programs[11]

Lack of survivorship knowledge and training	94%
Financial constraints	61%
Lack of administrative support	6%
Staff philosophy that excluded survivorship	15%

emulate efforts that advocate for cancer survivorship programs within their institutions and local communities.

REVIEW OF THE LITERATURE

Barriers to successful implementation of cancer survivorship programs are both institutionally based and patient-based. A foundation of data in this field is already evolving, but it needs to be expanded to include evidence-based models for monitoring adult cancer survivors and preventing the aftereffects of cancer treatments. A 2009 meta-analysis of retrospective data was combined with a prospective analysis of current US cancer diagnosis rates, the accrual rates for new chemotherapies prescribed versus the current number of clinic visits for cancer evaluations at the Dana Farber Cancer Institute, the career choices (general medicine vs specialty practice) of third-year medical students at the Dana Farber Medical Center, and current statistics regarding follow-ups by primary care physicians (PCPs) after chemotherapy within the Dana Farber medical system.[10] The study concluded that with current attrition rates, the number of doctors specializing in oncology will be insufficient to cover the needs of an increasing number of cancer survivors, and the number of PCPs will not meet the needs of an increasing population of cancer survivors. This study aptly identified a projected lack of trained oncology medical providers as a significant barrier to successful survivorship care.[10] As medical shortages evolve, nurses should become cognizant in recognizing the special needs of cancer survivors (Table 1).

Researchers at City of Hope National Medical Center investigated institutional barriers regarding cancer survivorship via a qualitative study with 156 oncology health care providers from 52 NCI cancers centers across the United States between 2006 and 2009.[11] The researchers created Preparing Professional Staff to Care for Cancer Survivors, a comprehensive training course designed to overcome institutional barriers regarding cancer survivorship care. Participants were nurses (48.1%), social workers (20.7%), physicians (18.0%), administrators/directors (6.6%), psychologists (2.8%), and others (3%).

Participants completed a precourse survey regarding their ideas and perceptions about cancer survivorship programs. The 4-day training course focused on quality of life, changing practice through performance improvement, and adult education. After completion of the course, participants were tasked with developing a cancer survivorship program at their respective institutions with assistance from the specialist faculty associated with the course. Postcourse evaluations and surveys conducted at 6, 12, and 18 month intervals identified the most common barriers to cancer survivorship programs[11] (Table 2). A lack of administrative support is the most significant challenge for many nurses. However, nurse

TABLE 3. IOM recommendations for cancer survivorship programs[16]

Program objectives should be to raise awareness of the needs of cancer survivors, establish survivorship as a distinct phase of care, and ensure delivery of appropriate care.
Patients should receive a comprehensive care summary with follow-up plans that are clearly and effectively explained.
Systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments should be used to identify and manage late effects of cancer and its treatment.
Health systems should develop quality of survivorship care measures through public and private partnerships and quality assurance programs to monitor and improve the care that all cancer survivors receive.
CMS, NCI, AHRQ, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.
Congress should support the CDC, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care and promote implementation, evaluation, and refinement of existing cancer control plans.
NCI, professional associations, and voluntary organizations should expand and coordinate their efforts to provide education to health care providers that equips them to address the health care and QOL issues facing cancer survivors.
Employers, legal advocates, health care providers, support service sponsors, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors who have short- and long-term limitations in their ability to work.
Federal and state policy makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and other third-party payors should recognize survivorship care as an essential part of cancer care. Design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.
NCI, CDC, AHRQ, CMS, the Department of Veterans' Affairs, private voluntary organizations such as ACS, and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care.

Key: ACS, American Cancer Society; AHRQ, Agency for Healthcare Research and Quality; CDC, Centers for Disease Control and Prevention; CMS, Centers for Medicare and Medicaid Services; IOM, Institute of Medicine; NCI, National Cancer Institute; QOL, quality of life.

involvement in institution-based committees that focus on developing and maintaining active survivorship programs can lead to positive change for these patients.

Institution-related issues are not the only barriers to successful integration of post-cancer-care treatment into practice. Patients' and providers' perceptions on how to transition to post-cancer-care treatment may also present as barriers. A team from Johns Hopkins School of Medicine interviewed 21 breast cancer survivors, their oncology care providers, and their primary care providers to determine the priorities and identified needs of all involved in terms of cancer survivorship outcomes.[12] The study utilized a semi-structured guide and focus group interviews. The interviews were transcribed verbatim and interpreted through qualitative thematic analysis into data on transition to follow-up care, provider-patient communication, patients' needs, and providers' roles.

In this study, survivors reported psychosocial and communication barriers with their PCPs, who were not familiar with the patient's cancer treatment history and were unaware of the difficulties experienced during treatment for cancer. Oncology care providers reported a frequent struggle with discharging patients at completion of treatment due to protective relationships, and primary care providers expressed concerns about having the time and training to provide adequate survivorship care, and communication issues with the patients' oncologists.[12] Nurses can be instrumental in bridging these communication gaps. They are charged with communicating discharge plans and ensuring that patients comprehend the prescribed plan of care; therefore, they can be an important and crucial element in ensuring that PCPs understand the patient's survivorship care plan.

Expanding further upon patient perceptions of social support and cancer survivorship in specific populations, Yoo and colleagues conducted qualitative studies to determine the impact a breast cancer diagnosis has on older women from ethnically and racially diverse populations.[13] In one study, the Yoo team surveyed 48 women breast cancer survivors aged 65 to 83 years. The participants were African American, white, Hispanic, and Asian American women. Study findings indicated that women age 65 to 70 years viewed cancer as an indication to improve their overall health status; women age 70 to 80 years felt cancer was part of the aging process and just another medical condition, and those older than 80 years reported more symptoms and greater concern about other comorbidities than about their cancer diagnosis. The study also revealed cultural and ethnic differences in perception of social-support needs of older female breast cancer survivors.[13] Age, race, and ethnicity can impact the success of cancer survivorship programs.

Other patient perception barriers were explored via qualitative design studies with a focus group of 22 African Americans aged 55 to 85 years.[14] The researchers explored perceived social support needs of older African American survivors of breast, colon, and prostate cancers. Misconceptions about cancer in general, negative cultural beliefs regarding cancer treatment, and fears related to cancer death were barriers to care in this patient population before, during, and after cancer treatment.[14]

THE CONTINUUM OF CARE

Early work in cancer survivorship by Mullan described three phases of cancer care: the acute phase, which begins at the time of diagnosis and includes testing and treatment; the extended or intermediate phase, which begins at remission and continues through the period of highest risk of recurrence; and a permanent or long term phase, which begins when the highest risk of recurrence has past.[15]

In 2006, the Institute of Medicine (IOM) identified cancer survivorship as a distinct entity in the cancer care continuum in its report *From Cancer Patient to Cancer Survivor: Lost in Transition*. The IOM outlined deficits in the care provided to cancer survivors and made recommendations for improving the mechanisms used to coordinate follow-up cancer care[16] (Table 3).Following the report, IOM presented a mandate calling for continued and expanded research for an evidence-based model for initiatives to address the unique needs of patients who have completed primary treatment of cancer that can be incorporated into practice.

Patterson pioneered a potential framework for cancer survivorship programs that transcends the phases identified by Mullan and incorporates strategies to overcome institutional, patient, and provider barriers.[1] Patterson's framework proposes the following course of actions for caring for patients after completion of primary cancer care:

- Identify care-team members who are familiar with and competent in recognizing the medical and emotional care needs unique to the oncology patient
- Create a cancer survivor program that incorporates patient-centered, multidisciplinary care based on the tenets of the IOM's recommendations for cancer survivorship care
- Identify the appropriate patient population for the program by determining phase of care based on Mullan's descriptions
- Conduct a thorough literature review including cancer surveillance, late effects of cancer, health promotion and recurrence prevention, and psychosocial functioning and quality-of-life concerns related to cancer survivorship.[1]

The construction and assembly of cancer survivorship care plans and documentation tools can also impose barriers.

Houlihan identifies the barriers that affect the successful execution of a cancer survivorship care plan the most as the ability to access information, preparation and completion time for busy clinicians, the absence of clearly stated guidelines for follow-up care after cancer treatment, and the lack of universally accepted language and content that is understood across the specialty of oncology.[17] Houlihan notes that these issues combined with the elements needed to ensure adequate documentation for third-party reimbursement are areas that need improvement. Due to a lack of research related to actual development of cancer survivorship care plans, Houlihan implies that as cancer survivorship care evolves and is more globally defined, oncology nursing professionals are at an opportune time to be catalysts in the development of new and universally accepted documentation tools and care plans.[17]

CONCLUSION

Survivorship research reveals that misconceptions about cancer in general amongst particular populations combined with negative cultural beliefs about cancer treatment and cancer death serve as significant barriers to the successful after-treatment care of cancer patients.[14] By incorporating these findings into ideals proposed by Patterson, oncology professionals should be able to recognize cultural fears and beliefs that may influence a patient's cancer experiences, while also recognizing that nursing competency and comfort with cancer survivorship care and education, and institutional belief in and support of the value of a cancer survivorship program, play important roles in the success of these programs.

Adopting these principles into any cancer survivorship program will ensure the success of these programs, while ensuring that universally accepted, clearly stated care plans are utilized for cancer survivorship patients. These principles can help overcome the barriers and obstacles to successful implementation of these programs. In order for oncology professionals to implement and maintain thriving cancer survivorship programs, efforts to collect data, pursue research regarding ongoing cancer care beyond primary treatment, and recognize the variables that may present barriers to these programs should continue. ■

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