
EVOLVING NURSING SCIENCE AND PRACTICE IN CANCER SURVIVORSHIP

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OBJECTIVES: *To review the status of cancer survivorship care planning and delivery, resources and tools available to advance care, and explore professional nursing's potential to affect the quality of care available to cancer survivors.*

DATA SOURCES: *Published peer reviewed literature, web-based resources, and cancer-related professional organizations' resources.*

CONCLUSION: *The population of cancer survivors is characterized as "booming," and available resources are also booming. Professionals involved in planning and delivering cancer survivorship care have access to tested tools, resources, information, and data useful for programmatic strategic planning and individualized survivor care plans. There are significant challenges to implementation, but there are also hopeful indicators that holistic care and services can be both cost-effective and used to improve care and quality of life for survivors.*

IMPLICATIONS FOR NURSING PRACTICE: *Nurses have significant roles in the planning and delivery of survivorship care. There are as yet no clearly defined pathways, guidelines, and standard metrics that reflect the value of these nursing roles, though there are interesting and intriguing early indicators of value that should stimulate the imagination of oncology nurses regardless of care setting, geographic location, and population to be served.*

KEY WORDS: *Survivorship care planning, survivorship care plans, nursing, oncology nursing*

WHEN Fitzhugh Mullen's paper, "The Seasons of Survival"¹ was published in the *New England Journal of Medicine* in 1985, few people recognized

it as a seminal moment in the history of cancer. But, 1 year later, Mullen and other former cancer patients founded the National Coalition for Cancer Survivorship (NCCS), a non-profit organization

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that was the first to pursue public policy efforts favorable to the needs of people facing the known and unknown challenges imposed by their diagnoses and treatment regimens. Following Mullen's lead, the NCCS charter defines *survivor* as: "From the time of discovery and for the balance of life, an individual diagnosed with cancer is a survivor."² This article reviews some of the challenges to providing survivorship care and discusses efforts to prioritize the most essential elements.

SURVIVORSHIP: THE FIRST 30 YEARS

Since its inception, NCCS's efforts focus on grass roots, state, and federal public policy arenas, advocating for increased public awareness of cancer survivorship as a distinct phase of the continuum of cancer, research efforts to identify and address unmet needs among survivors, and health policies that support advances in science and technology to find causes, prevent, and develop therapies to control and cure cancer. Now, nearly three decades after the NCCS was founded, at least 50 diagnosis-specific advocacy organizations exist in the United States—the Leukemia and Lymphoma Society and the Susan G. Komen Breast Cancer Foundation among them, most with missions that relate to finding cures. A few, most notably LIVESTRONG™, support strong survivorship agendas.

The 1996 designation of the National Cancer Institute's Office of Cancer Survivorship³ represents yet another seminal event in the evolution of cancer survivorship, drawing increased recognition of survivorship issues, and incentivizing survivorship research programs. The first national Conference on Cancer Survivorship Research was held in 2002, and is re-convened on a biennial basis. Jointly hosted by the Office of Cancer Survivorship, LIVESTRONG (formerly the Lance Armstrong Foundation), and the Centers for Disease Control, this conference brings together investigators, clinicians, survivors, caregivers, policy-makers and public health experts to share the most recent cancer survivorship research.⁴

Additional incentives to make cancer survivor care and research priorities in America were three pivotal reports submitted by the President's Cancer Panels. In 2002, *Voices of a Broken System: Real People, Real Problems*, documented fragmentation in America's cancer care delivery that contributes to disparities and subsequent sub-optimal outcomes among Americans affected

by cancer.⁵ The 2003-2004 report, *Living Beyond Cancer: Finding a New Balance*, was the first such effort to focus on the challenges of cancer survivorship.⁶ Between 2009 and 2010, the Panel explored disparities in cancer outcomes relating to ethnic sub-populations, health status and socioeconomic differences, environmental degradation, and immigration impact of changing U.S. demographics, resulting in *America's Demographic and Cultural Transformation: Implications for Cancer*.⁷

In July 2005, the *American Journal of Nursing* (AJN), in collaboration with the American Cancer Society, the National Coalition for Cancer Survivorship, and the University of Pennsylvania School of Nursing, convened the "State of the Science symposium on Nursing Approaches to Managing Late and Long Term Sequelae of Cancer and Cancer Treatment," and publication of an AJN supplement of the same title in 2006.⁸ Symposium planners aimed to build on reports identifying needs and gaps in research on cancer survivorship. Table 1 summarizes outcomes of the State of the Science Symposium.

Between 2004 and 2005, the National Academy of Science Institute of Medicine (IOM), acting on a request from the United States Congress, explored the status of cancer survivorship in the US, culminating in the widely circulated report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,⁹ published in 2006. The IOM report focused on survivors of adult cancers after completion of initial treatment with no evidence of disease. The intent of the report was to raise awareness of the sequelae of cancer and cancer treatment, define high-quality health care for survivors, and improve quality of life for the survivor population. Table 2 highlights the IOM report's 10 major recommendations. The IOM report identifies essential components of survivorship care as:

- 1) Prevention of recurrent and new cancers, and other late effects.
- 2) Surveillance for cancer spread, recurrence, or second cancers, and assessment of medical and psychosocial late effects.
- 3) Intervention for consequences of cancer and cancer treatment.
- 4) Coordination between specialists and primary care providers to ensure survivors' health needs are met.⁹

Of the 10 IOM report recommendations, Recommendation 2, at the time, seemed most achievable:

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