Survivorship Care: More Than Checking a Box

In 1987, the 12th Annual Oncology Nursing Society (ONS) Congress held in Denver, Colorado, featured a session moderated by Deborah A. Boyle, MSN, RN, AOCNS®, FAAN, with Fitzhugh Mullan, MD, and Susie Leigh, BSN, RN, cofounders of the National Coalition for Cancer Survivorship, titled “The Seasons of Survival,” which was one of the earliest presentations to oncology nurses that proposed cancer was not necessarily a deadly disease and that nurses could address the needs of survivors. As an advanced practice nurse (APN) in oncology hearing this presentation, I began to look at long-term needs of survivors who had advanced beyond acute care and benefited from effective treatments. Cancer survivorship now is a priority in oncology clinical practice.

In 2006, the Institute of Medicine (now the National Academies of Sciences, Engineering, and Medicine) released From Cancer Patient to Cancer Survivor: Lost in Transition, a report that included 10 recommendations to enhance the care of the growing survivor population transitioning into life post-treatment. The report raised awareness about survivor needs, with recommendations to establish survivorship care plans in practice and to improve professional education about the needs of this population.

Since 2015, when the American College of Surgeons (ACS) implemented a standard that required survivorship care plans for cancer survivors, healthcare systems have scrambled to establish survivorship care plans in practice (Stricker & O’Brien, 2014). Although the ACS standard has been modified, healthcare facilities still require variations of survivorship care plans in practice.

Why is it important for clinicians to champion survivorship care, which includes care plans that go beyond checking a box on a checklist? Here is an example from my practice: In preparation for a genetic counseling session with a patient who had early-onset colon cancer, I reviewed the patient’s health record, and there was no information about genetic testing, including whether it had been offered. During my visit with the patient, she shared her care plan, which had a box checked that confirmed family history of cancer. This was correct. However, the box for genetic testing/counseling was not checked.

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Survivorship care is complex. The institution where this patient received care achieved the goal of providing the patient with a survivorship care plan, but there was a significant disconnect between the assessment (family history of cancer) and appropriate intervention (referral for genetic counseling). The value of the care plan is diminished if it does not lead to interventions that ensure the best possible care for survivors. Survivorship care is more than checking a box in a patient’s chart or care plan that satisfies requirements for accreditation and then handing the patient a piece of paper at the end of an appointment.

This supplement results from those observations. It captures a now-sturdier, updated foundation about clinical care of cancer survivors in two main sections. The first is a deep-dive comprehensive review of cancer- and treatment-related long-term symptoms or issues related to survivorship care. Compiled by APNs, the reviews about chest pain, sexual dysfunction, dyspnea (shortness of breath), germline (hereditary) predisposition to cancer, and bone loss/osteoporosis in cancer survivors were selected because the standards of care and guidelines about these topics are still evolving.

This section also briefly reviews 11 selected symptoms that already have a foundational basis in practice, as evident by guidelines, standards of care, and established resources. These symptoms are cognitive dysfunction, distress, fatigue or lack of endurance, constipation, gastrointestinal distress, hot flashes, lymphedema, peripheral neuropathy, pain, skin toxicities, and sleep–wake disturbance. These reviews briefly highlight the selected symptoms and emphasize links to guidelines and more fully developed resources.

In the second section, a panel of APNs commented on four case studies of survivors, representing four common cancer diagnoses (i.e., breast, colon, and prostate cancers and a hematologic malignancy) in an effort to create a fresh conversation about approaches and clinical strategies to care for cancer survivors.