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# LIVING WITH MULTIPLE MYELOMA: A CONTINUUM-BASED APPROACH TO CANCER SURVIVORSHIP

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**OBJECTIVES:** *To describe a tailored approach to survivorship care for health care providers (HCPs) involved in the care of patients and caregivers living with multiple myeloma (MM) and identify key transition points within the continuum of care with recommended adaptation to the survivorship care plan (SCP).*

**DATA SOURCES:** *Review of the literature, web-based resources.*

**CONCLUSION:** *The health care needs of cancer survivors will vary throughout the continuum of care. Effective patient self-management requires several key elements: consistent and clear communication that allows the patient to make informed decisions, reinforcement of key messages at each visit, adjustment of visit frequency to the specific phase of survivorship and health care needs, integration of community programs and resources, and development of mutually determined goals. The goal is to focus on living, maintaining or improving quality of life (QOL) in the MM survivor with consideration of the needs of caregivers.*

**IMPLICATIONS FOR NURSING PRACTICE:** *Implementation of a tailored survivorship care plan (SCP) based on individual disease- and treatment-related factors, personal preferences, and available resources, setting expectations, and continuing to communicate openly with the MM patients and their caregivers promotes health-self-management, reduces symptom burden, and improves QOL. Innovative strategies for survivorship care that promote communicative health*

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*literacy, engage the patient and their caregivers in health self-management, involve the survivor in developing the SCP, and clearly designate the roles of HCPs are needed.*

**Key Words:** *survivorship, transition points, multiple myeloma, caregivers, communication.*

Any person diagnosed and living with cancer is a cancer survivor. The goals for supporting these individuals should focus on living and feeling well while incorporating personal goals and individual preferences. Cancer survivorship does not just affect the person with cancer.[1] Realistically, you cannot separate patients and their caregivers in the continuum of care; therefore, interventions that provide support for the caregivers are essential. Since the inception of the survivorship movement, driven by the Institute of Medicine (IOM) report "From Cancer Patient to Cancer Survivor: Lost in Transition",[2] cancer institutions, regulatory agencies, and advocacy organizations have attempted to develop survivorship programs and metrics for measuring patient outcomes.[3-6] The inaugural survivorship programs were grounded in the belief that individuals diagnosed with cancer had completed treatment and required a tailored plan for health promotion, monitoring for and management of late effects of treatment, and support for the psychosocial aspects of being a cancer survivor.[7-9] Recommendations included development and implementation of interdisciplinary evidence-based clinical practice guidelines, multidisciplinary health care teams, and communication strategies that address cancer survivors' health care needs throughout the continuum of care.[5,9,10] Unfortunately, many of the early cancer survivorship programs, primarily in large academic institutions or health care systems, were unsuccessful in meeting the lofty goals set forth. The time required for completion of the original SCPs and difficulty in establishing ownership of elements of care among the varied health care professionals involved in survivorship care were the most common reasons cited.[3,6]

The health care needs of cancer survivors will vary throughout the continuum of care.[7,9] Patients' perceptions of who should take the lead role in managing each of these needs may vary throughout their lifetime. In addition, patients' age, caregiver support, socioeconomic status, and cultural, spiritual, and health care beliefs will also affect how and when they utilize health care provider (HCP) services.[11] Add to this the variability in survivor preferences for who they believe is best suited to manage their survivorship needs, and the development of research based guidelines for tailoring survivorship care is clear. However, research-based guidelines require participation in clinical trials and research studies. Unfortunately, the estimated clinical trials enrollment in the United States for cancer patients is approximately 4% of the total cancer patient population. When considering rare diseases such as myeloma, this number is estimated to drop below 2.5%.[12] Furthermore, previous survivorship models have limited application to many diseases, including myeloma, where treatment for life, either continuous or episodic is expected.[9,13-15]

Cancer survivors are faced with complex decisions throughout their survivorship journey relative to their cancer diagnosis, other comorbid conditions, finances, and how they choose to participate in their care. Visit times to HCPs are often just 15–20 minutes, making it difficult to communicate complex ideas in a way that patients and their caregivers will be able to understand, synthesize, and use information to make informed decisions about their care.[13] Patients with multiple health problems, common in older cancer patients, may have difficulty understanding the complexity of balancing their cancer treatment with the continued management of existing illnesses. Yet, HCPs expect patients and family members or other designated caregivers to assume a primary role in managing their illnesses, including adverse events, reporting signs and symptoms, communication between providers, and continuing to take an active role in decision making.[16] There is an anticipated shortfall of practicing oncologists in the next decade, yet cancer survivors in the United States are estimated to exceed 20 million people by 2026.[17] If we consider the inclusion of even one caregiver per survivor in this estimate, the number of individuals living with a personal diagnosis of cancer or with a cancer survivor becomes staggering. Therefore, innovative strategies for survivorship care are imperative.