SURVIVORSHIP CARE PLANNING: ONE SIZE DOES NOT FIT ALL

Jennifer R. Klemp

<u>OBJECTIVES:</u> To describe the delivery of survivorship care and methods to stratify risk to support the notion that "one size does not fit all."

<u>Data Sources:</u> Published articles between 2007 and 2014 and original research findings.

<u>Conclusion:</u> The development and implementation of survivorship care into practice provides barriers and opportunities. National mandates are pushing the delivery of a survivorship care plan, which requires the ability to develop and deliver this tool and the necessary health care delivery model to manage the unique needs of each cancer survivor.

<u>IMPLICATIONS</u> FOR NURSING PRACTICE: Oncology nurses and advanced practice nurses will play a crucial role in the development of survivorship care from education and assessment to the delivery of coordinated care.

KEY WORDS: Cancer survivorship, models of delivery, survivorship care plan

ITH a growing number of cancer survivors and the push to meet national accreditation standards, we have an opportunity to explore methods of delivering survivorship care based on level of risk and need. One challenge is there are currently few models for stratifying risk of physical and psychosocial effects of cancer and its treatment. This is a crucial gap to fill to more effectively manage survivors and their caregivers and to lower overall health care costs.

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Personalized Survivorship Care

Currently, the diagnosis and treatment of cancer includes imaging, biomarker-driven targeted therapies, genetic and genomic tests used to stratify risk of cancer, need and response of treatment, risk of recurrence, and improve survival. The treatment plan requires careful investigation, discussion, and influence of multiple experts and is individualized to the patient. The push to provide this same level of detail and personalization to those who complete planned treatment has been suggested and mandated by experts in the field and national accrediting organizations such as the American College of Surgeons Commission on Cancer Program Standards for 2012 (implementation by 2015) and the American Society of Clinical Oncology's Quality Oncology Practice Initiative Standards. 1,2

The Survivorship Care Plan (SCP) theoretically has the ability to serve as a document for knowledge transfer and facilitate the delivery of shared care.^{3,4} The SCP is the road map for the delivery of survivorship care, which must be individualized and delivered in a health care delivery system that can manage the multidisciplinary physical and psychosocial needs of cancer survivors. Most of the research to date on SCPs has focused on the development, content, implementation, delivery, and theoretical benefit.⁵ There is a need for studies evaluating patient-centered outcomes and models of health care delivery. This type of research is complicated and requires a high level of organization. In addition, the location of delivery also needs further evaluation including rural,⁶ community-based, hospital-based, and academic medical centers. Each location of delivery has differing levels of expertise, access to multidisciplinary care including specialists and primary care providers, and community resource and supportive care organizations.

Guidelines for surveillance and physical and psychosocial needs are established but not consistently implemented and evaluated. Clinical practice guidelines for cancer survivors have been developed by the American Society of Clinical Oncology (ASCO) and the Children's Oncology Group, both providing evidence-based consensus recommendations for certain types of cancer. These practice guidelines, along with cancer screening guidelines and health promotion from organizations including the American Cancer Society, serve as part of a comprehensive framework in the delivery of survivorship care. The National Comprehensive Cancer Network has also released recommendations to assess distress and survivorship (V2.2014). These guidelines cover topics including assessment for anxiety and depression, cognitive function, exercise, fatigue, immunizations and infections, pain, sexual function, and sleep disorders, and are designed to provide a framework for general survivorship care and management and are not intended to provide specific guidelines on the surveillance and follow-up requirements for a survivor's primary care. Having access to guidelines and recommendations promotes the delivery of patient-centered, coordinated care, and requires ongoing evaluation of outcomes.

Lastly, the demands of caring for cancer survivors, both with and without active disease, require time and an understanding of potentially complex issues. With a shrinking oncology work force there is a push to use a shared care delivery model. Unfortunately, there is also a shrinking work force in

primary care and pressures for an increased number of patient visits per day. The result is an oncology visit focused on surveillance for recurrence or disease progression and may target a specific issue or concern. From the primary care perspective, they may lack knowledge of screening guidelines and strategies to manage complex issues of cancer survivors. Further, a clear delineation of which provider is responsible for aspects of follow-up care is often ill-defined. 10,11

Models of Care

The delivery of survivorship care may differ within and between health care delivery systems. Table 1 summarizes models of delivery and the likely survivors and providers within each model. 3,12-17

Without evidence supporting outcomes, there is not a standard model that will work even within a single organization. To address the individual needs of cancer survivors, there must be flexibility in implementing models of care.

Figure 1 depicts the patient journey where survivorship care begins at the time of diagnosis and continues during active treatment, into continuity of care for long-term cancer survivors. This figure also highlights the complexity of delivering survivorship care along the cancer continuum and the need for a network to care for cancer survivors. A focus on earlier implementation of education and intervention from the time of diagnosis is consistent with the current definition of a cancer survivor, "from the time of diagnosis through the lifespan."18 Organizations should begin development of a survivorship program by first evaluating what aspects of survivorship care already exist within or outside the organization. This inventory will result in many aspects of care that may or may not be integrated and accessible to cancer survivors and providers. The next step is to identify what elements of survivorship care require process improvement or need to be developed.

To make this process easier to conceptualize, cancer survivorship should be regarded as a chronic health condition using the chronic health care model (similar to the management of cardio-vascular disease and diabetes), ¹⁹ which can provide a necessary framework for the delivery of survivorship care and self-management. This may also include incorporation of the oncology patient-centered medical home²⁰ and other

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