

National Cancer Survivorship Resource Center

Systems Policy and Practice: Clinical Survivorship Care

Expert Panel Summit Workgroup Overview

National Cancer Survivorship Resource Center

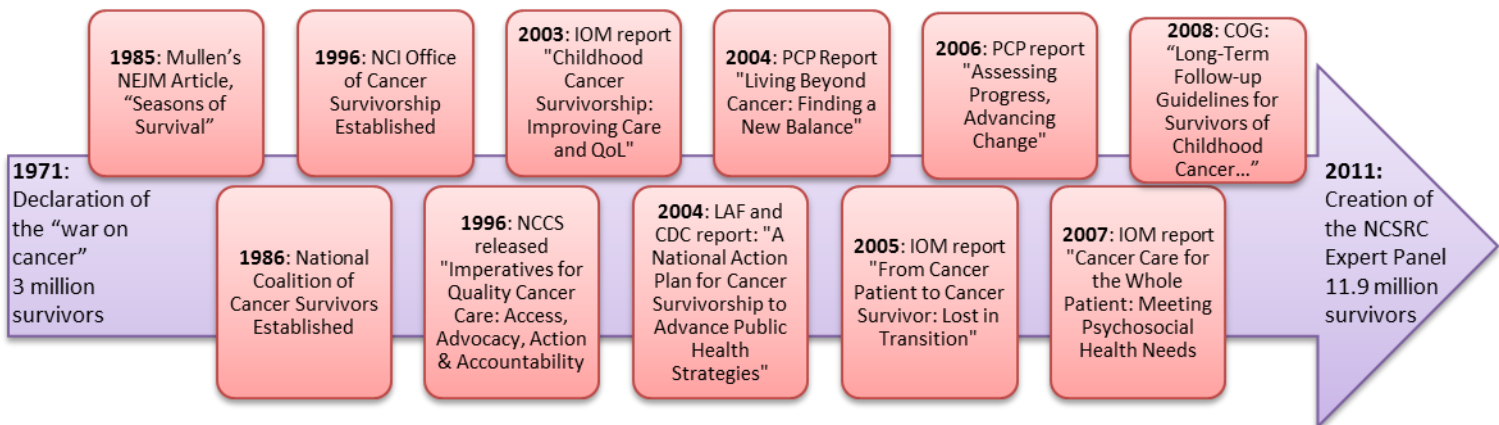
Systems Policy and Practice: Clinical Survivorship Care Overview

Cancer Survivorship: Clinical Care and Follow-up

Evolution of Cancer Survivorship

Research advancements in cancer prevention and treatment have helped pave the way towards establishing survivorship as a distinct phase in the cancer continuum. A particularly significant advancement in cancer research was realized in 1971, when President Richard Nixon signed the National Cancer Act. Figure 1 provides a snapshot of the development of survivorship as a phase of cancer care and the declaration of cancer survivors as a specific population with new clinical and psychosocial needs.

Figure 1: Evolution of Cancer Survivorship



Clinical Survivorship Standards of Care

Even with the recommendations and reports highlighted in Figure 1, neither consensus- nor evidence-based guidelines for adult survivorship care have been clearly established. Several barriers exist in the development of clinical survivorship care guidelines to ensure a comprehensive and coordinated approach to address the needs of cancer survivors.

- Survivors are a rapidly growing population with a diverse subset of cancers and cancer treatment protocol. As this population has grown, organizations have had to adapt to meet the needs of cancer survivors. The diversity of survivors, their needs and the survivorship treatment models currently in use make it difficult to identify a single protocol for clinical survivorship care that will meet the needs of survivors and the health care professionals providing their care (McCabe and Jacobs, 2008; Landier, 2009).
- There is limited longitudinal surveillance as well as prospective research studies of patients throughout the cancer continuum. The lack of long-term population based tracking of physical and psychological impacts combined with continuous advances in treatments leave the possibility of many unknown late and long-term side effects. This lack of surveillance and research is cited as the overarching limitation to establishing evidence-based clinical practice guidelines. Additionally, the void has also led to limited education and awareness among health care professionals as to the psychosocial and clinical needs of survivors.

National Cancer Survivorship Resource Center Systems Policy and Practice: Clinical Survivorship Care Overview

- While primary care providers (PCPs) are generally willing to accept the responsibility of caring for survivors after primary treatment ends, without clear clinical guidance, mechanisms of communication (e.g. survivorship care plan) and effective coordination with oncology specialists, nursing and other health professionals, this care will not be optimal (Del Giudice, 2009). Smooth care transitions are critical to maintaining positive patient-provider relationships. The lack of a defined leader of care leads to confusion among survivors, PCPs, oncology specialists, nurses and other health care professionals as to who is responsible for various aspects of follow-up care (Cheung et. al, 2009; Ganz et. al., 2008).

Despite these barriers, work has continued toward the development of clinical guidance for the care of cancer survivors. The 2006 Institute of Medicine (IOM) Report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, devoted a chapter toward the importance of clinical care guidelines and gathered evidence on follow-up standards that currently exist for breast, colorectal and prostate cancers (IOM, 2006). This portion of the report and the emphasis on the importance of survivorship care plans led to a follow-up meeting focused on implementing cancer survivorship care planning. The 2007 update to the *Lost in Transition* Report provides an overview of developing clinical survivorship care guidelines, highlighting perspectives from the development of guidelines for childhood cancer survivors and American Society of Clinical Oncology's (ASCO) initiative to develop adult cancer survivorship guidelines (IOM, 2007). Combined with the National Comprehensive Cancer Network (NCCN) guidelines on distress, fatigue, pain and palliative care, a movement toward the development of both evidence and consensus-based guidelines in survivorship care is slowly emerging (Jacobsen, 2009).

As highlighted by the IOM and others, the surveillance and research void creates a gap in health care professional knowledge of common cancer survivor needs and late effects (IOM, 2006). This gap in knowledge is magnified by the rapidly growing population of cancer survivors and the decreasing availability of oncology and primary care providers (IOM, 2009). Education on the needs of cancer survivors, training on how to teach survivors self-management techniques and the need for clinical practice guidelines are all critical to effectively provide quality care to this growing survivor population in the midst of a workforce shortage (IOM, 2009). The Systems Policy and Practice: Clinical Survivorship Care workgroup began discussions with these critical needs in mind.

Workgroup Progress: A Plan for the Development of Clinical Survivorship Care Guidelines

The Systems Policy and Practice: Clinical Survivorship Care Workgroup identified two priority areas of focus: clinical survivorship care guidelines (either evidence- or consensus-based) and health care professional education. The group identified these focus areas through a series of discussions and follow-up questions. The number one priority identified was the development of clinical survivorship care guidelines. When asked to rank what each member thought the National Cancer Survivorship Resource Center (The Survivorship Center) should accomplish in four years, respondents cited clinical survivorship care guidelines twice as often than other priorities such as survivorship care plans, raising awareness of survivors' needs, education and health care professional trainings. Similarly, when asked what subgroup the workgroup member would like to join nearly 75% of workgroup members listed the

National Cancer Survivorship Resource Center Systems Policy and Practice: Clinical Survivorship Care Overview

guidelines subgroup as the first preference. Furthermore, the priority need of clinical survivorship care guidelines was a primary discussion topic of nearly every workgroup meeting.

A subgroup was created to begin developing site-specific and psychosocial guidance grids, leveraging earlier work published in Kattlove and Winn's 2003 article "Ongoing Care of Patients after Primary Treatment for Their Cancer" (Kattlove and Winn, 2003). The subgroup identified four critical post-treatment phases: - 0-2 years, 2-5 years, 5-10 years, and >10 years post-treatment. The subgroup then agreed to focus efforts on defining potential issues and care for various tumor sites during the 0-5 year post-treatment survivorship period. The subgroup's work aimed to gather and enhance existing clinical survivorship care guidance to inform health professional education and to catalyze more rigorous guideline development in collaboration with other organizations (e.g., NCCN, ASCO). Guidance for the 0-5 year post-diagnosis period was identified by the subgroup as the area most critical for both survivors and health care professionals. Grids summarizing cancer site specific complications, existing clinical care guidelines or common practices, interventions and education were drafted by several workgroup members and other expert volunteers for cross-cutting quality of life issues (distress/depression and financial issues), brain cancer, breast cancer, cervical cancer, colon and rectal cancers, head and neck cancers, Hodgkin's lymphoma, leukemia/Non-Hodgkin Lymphoma, lung cancer, ovarian cancer, and prostate cancer. The creation of an strategic plan to facilitate guidelines development will be the focus of The Survivorship Center Expert Panel Summit.

Health Care Professional Education

The workgroup also examined health care professional education. The workgroup discussed the implications of training health care professionals without clear guidelines, but ultimately agreed on the need to educate health care professionals about survivorship care, survivor needs and available resources based on information currently available while post-treatment clinical survivorship care guidelines continue to be developed.

The workgroup compiled an inventory of existing survivorship-related trainings and discussed the potential for enhancing health care professional education and certification/accreditation after post-treatment clinical survivorship care guidelines are developed. The workgroup also discussed the importance of incorporating guidelines or recommendations into survivor care plans and electronic medical records to increase compliance and adoption of the new clinical care guidance.

Another important aspect of health care professional education is the need to determine a "captain of the ship" for survivorship. The workgroup discussed the various models of survivorship care and concluded one specific care model could not be recommended at this time. Even within the workgroup members' own organizations, different models are in use across departments. However, it is important, in every model, to clearly define the primary health care professional point of contact for the survivor's care and establish a medical home for that care. This, along with appropriate care coordination, is the key message that should be included in health care professional education and training.

National Cancer Survivorship Resource Center Systems Policy and Practice: Clinical Survivorship Care Overview

Recommendations for the Future

The workgroup developed a recommendations matrix that included recommendations, performance indicators and identified gaps. The matrix is structured using the socio-ecologic framework, focusing on individual/survivor, organization/health care system and society/policy levels of intervention in the four essential areas of survivorship care: healthy habits, early detection/disease surveillance, psychosocial and physical post-treatment side effects and provider communication. These recommendations are described in the following section.

Survivors: The Clinical Survivorship Care workgroup focused on opportunities for health care system and societal policy change. The workgroup recognizes the importance of individual/survivor level recommendations as an essential component of a multi-level strategy to improve survivorship care. The workgroups recommendations support recommendations put forth by the quality of life workgroups.

Health Care System: The workgroup recommends survivorship care guidelines be developed for survivors' clinical and psychosocial needs. The workgroup also recommends that the provision of survivorship care plans for each survivor transitioning to the post-treatment period become a routine aspect of clinical oncology practice. The workgroup supports the refinement of chronic disease self-management models tailored to the needs of diverse cancer survivors as a means of empowering survivors to self-manage survivorship care. Finally, the workgroup recommends ongoing education and training of health care professionals on the importance of survivorship care, health care professional-health care professional and health care professional-survivor communication, consistent care coordination and best practices.

Society/Policy: In order to optimize clinical care practice for cancer survivors, the workgroup recommends reimbursement for those services determined essential in existing and future post-treatment clinical survivorship care guidelines. Without proper reimbursement there will be little economic incentive for health care professionals to administer the care recommended in the guidelines due to time constraints and workforce shortages. The workgroup also recommend advocacy efforts to ensure access to appropriate care for all cancer survivors. As integrative care models are developed, the workgroup recommends incentives for quality care coordination.

Indicators to Help Measure Progress

In order to evaluate and monitor progress on the group's recommendations, the following performance indicators were developed based on the workgroup discussions and strategic matrix. Additional work is needed to determine the specific measures, establish baseline value and set specific outcome goals for each of the performance indicators. An assessment of the current capacity of nationwide surveillance systems to support the measurement of these indicators is underway; once capacity is determined, recommendations for measures or proxy measures corresponding to each performance indicator will be developed.

**National Cancer Survivorship Resource Center
Systems Policy and Practice: Clinical Survivorship Care Overview**

Table 1: Clinical Survivorship Care Performance Indicators

Outcome Domain	Outcome Goal
Healthy Habits	Increase in number of health care professionals educating cancer survivors about healthy habits
	Increase in number of cancer survivors utilizing disease self-management
	Increase in number of health care professionals educating cancer survivors on self-management strategies
Early Detection / Disease Surveillance	Increase in number of health care professionals adhering to recommended screening guidelines
	Increase in number of cancer survivors receiving quality, timely follow-up and preventive health care
	Increase the number of underserved minority cancer survivors accessing follow-up surveillance and screening
Post-Treatment Side Effects (Psychosocial and Physical)	Increase in number of health care professionals adhering to post treatment clinical survivorship care guidelines
	Increase in number of cancer survivors receiving quality, timely follow-up for management and prevention of side effects
Health Care Professional Communication	Increase in health care professional communication through the use of integrated EMRs
	Increase in health care professional - to - health care professional communication and health care professional - to - survivor communication through the use of survivorship care plans

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**National Cancer Survivorship Resource Center
Systems Policy and Practice: Clinical Survivorship Care Overview**

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6 | Page

