Survivorship Programs and Care Plans in Practice: Variations on a Theme

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Abstract

Purpose: This qualitative study examined cancer survivorship programs at four health care organizations in Los Angeles County, CA: an academic medical center, a community hospital, a primary-care medical group, and a county hospital. The purpose was to describe the successful implementation of four distinctly different models of care, focusing on the creative development and use of the Institute of Medicine–recommended survivorship care plan (SCP) document in each setting.

Methods: In-depth semistructured interviews were done with survivorship teams to characterize each program and the development and use of the SCP at each institution.

Results: Each survivorship program has developed and implemented unique types of SCP documents. Specifically, a com-

prehensive SCP at the academic center, completed by the clinical team, which covers many facets of cancer survivorship; a patient-directed SCP at the community hospital, completed by the survivor with assistance of an oncology nurse and focused on treatment history and appropriate surveillance; an adapted ASCO SCP template at the primary-care medical group, completed via a partnership with contracted oncologists and focused on the treatment history, surveillance, and shared care between oncology and primary care; an adapted ASCO SCP template at the county hospital, completed by the survivorship nurse practitioner and focused on patient education, post-treatment care, and institutional care coordination.

Conclusion: The SCP document is a flexible tool that can be successfully adapted for use in extremely varied settings, from primary care to hospitals, to inform and educate patients and providers alike.

Introduction

The Institute of Medicine report on cancer survivorship, *From Cancer Patient to Cancer Survivor: Lost in Transition*, spurred interest in developing post-treatment cancer survivorship clinics and services that target the unique issues of the cancer survivor population.¹ Since the release of the report in 2006, many different models of survivorship care have been proposed in the literature and implemented at cancer centers and other health care organizations across the United States. A key recommendation from the report is the creation of a survivorship care plan (SCP) for every patient that summarizes the cancer treatment history and makes recommendations for surveillance and future care. In an effort to provide practical information on the development and use of SCPs, this study describes four different programs of survivorship care—at an academic medical center, a community hospital, a primary-care medical group, and a county hospital—and their development and use of unique SCP documents.

There are currently estimated to be 11.4 million cancer survivors in the United States²; as this number continues to increase with the aging population, the care and well-being of cancer survivors will become a priority in health care and in national health policy. It is well established that post-treatment cancer survivors are at risk for a multitude of physical and psychosocial long-term and late effects of treatment: Adult and pediatric cancer survivors may be at increased risk for cardiac issues, persistent fatigue, chronic pain, anxiety, secondary neoplasms, infertility, anxiety and depression, and many other problems.^{3–17} The recent Institute of Medicine report on cancer survivorship found that many cancer survivors do not receive

appropriate post-treatment care and that there is rarely a clear post-treatment care plan in place at the end of treatment. The report makes 10 specific recommendations for high-quality cancer survivorship care; one key recommendation is the creation of a cancer treatment summary and SCP document for every patient to facilitate post-treatment surveillance and coordination of care and to empower the patient and the health care team.

Although several excellent articles outline the major types of survivorship care program models (consultative, ongoing follow-up care, and integrated care),^{18–20} there is little information about the practical development and use of these highly recommended SCPs. Different models of survivorship care may demand different types of SCPs as a result of institutional setting, organizational priorities and goals, patient population, and available resources. This study gathered data on four distinctly different models of survivorship care and their associated unique SCPs: an academic medical center with a National Cancer Institute–designated comprehensive cancer center, an American College of Surgeons–accredited community hospital, a primary-care medical group with more than 600,000 covered patients, and a county hospital that serves low-income and uninsured patients.

Methods

This qualitative study used in-depth, semistructured interviews with the existing survivorship program teams at each of the four institutions to characterize the survivorship program and the development and use of the SCP at each institution. Those interviewed included clinicians such as oncology nurse special-

ists, social workers, and nurse practitioners, as well as administrative personnel such as program coordinators and quality improvement staff. Institutional review board approval was obtained to analyze the interview data.

Results

Survivorship Programs

The four survivorship care programs are quite distinct from one another. Although there is a common mission across the four institutions to provide high-quality post-treatment care to cancer survivors, there are differences in patient population, program staff, and organizational approach to providing survivorship care. Please see Table 1 for a brief overview of the core survivorship program components at each institution.

Academic center. The survivorship program in place at the academic medical center has three components: clinical care, community education and outreach, and research. The clinical care program offers three multidisciplinary clinics for all disease types and serves pediatric, adolescent/young adult, and adult cancer survivors. These three clinics are designed to address both physical and psychosocial needs of cancer survivors who are currently disease free and have completed active treatment (with the exception of long-term hormonal therapy). Patients are seen for comprehensive consultations with the adult survivorship team: medical oncologist, nurse practitioner, and psychologist and/or oncology social worker.

The goals of the survivorship consultation at the academic center are to provide education and counseling to the patient on a variety of survivorship issues such as management of long-term and late effects, general health and wellness, psychosocial and emotional health, appropriate surveillance screening schedules, and genetic testing. For pediatric cancer survivors, patients are observed annually because of the high burden of long-term and late effects experienced by this population. All patients are screened for depression using the widely validated Patient Health Questionnaire²¹⁻²⁴; they also complete the Rapid Eating and Activity Assessment for Patients questionnaire, a short, validated questionnaire on daily nutrition and activity designed for use in busy primary-care practices.^{25,26} Patients are provided with an extensive resource packet during the visit and are encouraged to follow up with the nurse practitioner with any questions or further concerns. Patients are referred to the survivorship program through a variety of mechanisms: oncology, primary care, and patient self-referral.

Community hospital. A different program was developed at the community hospital, where the survivorship team may have contact with cancer patients only at certain points during the cancer care journey. They choose to focus on patients diagnosed with breast cancer, usually through the hospital breast imaging center. Led by an oncology clinical nurse specialist, the survivorship program has found creative ways to reach out to its survivor population and provide survivorship education, tools, and counseling using a telephone and mail-based intervention.

Once a patient is identified (initially through use of a tumor registry listing), survivorship materials are mailed out in three phases: at the initiation of treatment, transitioning from active treatment, and post-treatment. Finally, the oncology nurse specialist contacts the patient via telephone to answer questions, discuss symptoms, perform surveillance, and provide referrals as necessary.

A follow-up letter is sent by the oncology nurse specialist to the patient with specific materials discussed during the phone call to help manage the patient's post-treatment effects, such as patient action plans on managing common survivorship issues (menopausal symptoms, fatigue, etc). The oncology nurse is then available to the patients via telephone or in person if late effects arise. Patients are referred to the program from the hospital diagnostic center and from the radiation oncology and surgical clinics.

Primary-care medical group. The primary-care medical group faced a similar problem with implementing survivorship care as the community hospital: much of the care takes place outside of the organization in contracted oncology groups. Creative solutions were needed to implement a survivorship program in a primary-care setting that includes patient counseling, education, and the use of a cancer treatment summary and SCP. The survivorship team, jointly developed and led by a clinical social worker and a quality improvement manager, recognized that the medical group has a strong tradition of and infrastructure for patient education, such as chronic disease management for diabetes, and built the survivorship program accordingly.

The program is designed to reach out to newly diagnosed breast cancer patients and provide ongoing resources, support, and education throughout the cancer journey. Similar to the community hospital, a three-phase intervention was designed to use telephone and mail contact with patients, with ongoing support available from the clinical social worker on the survivorship team. In addition, health education classes for patients are planned on a variety of survivorship topics such as nutrition and physical activities, psychosocial health, and managing common post-treatment symptoms. Patients are generally referred to the program by primary-care physicians or through the imaging center. The survivorship team also plans to expand the survivorship program to other disease types in the near future.

County hospital. The county hospital has a very different patient population and organizational challenges compared with the community organizations. Many patients face significant cultural and language barriers to accessing health care and may have unmanaged chronic conditions such as hypertension and diabetes. Patients tend to present with larger tumors and more advanced disease than in other treatment settings, and for some patients the county oncology program is their entrance into the health care system. Within the county hospital, surgical clinics had been observing breast cancer survivors and had become crowded with follow-up visits to manage post-treatment symptoms and provide surveillance. The survivorship program, developed and

Table 1. Survivorship Program Components Across Four Health Care Organizations

Organization Type	Survivorship Program	Providers	Partnerships	Patient Population
Academic medical center	In-person clinical evaluation with multidisciplinary team; pediatric cancer survivors observed, adult survivors have one-time consult	Medical oncologist, nurse practitioner, psychologist, social worker	Faculty practice medical group, local center for integrative oncology	All cancer types for adult and pediatric cancers; available to medical center patients as well as patients treated elsewhere
Community hospital	Nurse-led, telephone-based program; survivors also receive mailings and follow-up calls	Oncology-certified registered nurse	Local physician-owned oncology network	Breast cancer survivors; available to hospital and medical group patients
County hospital	Nurse-practitioner–led clinical program; survivors assessed, followed and primary care needs addressed	Nurse practitioner	In-house Avon Breast Navigation Program	Breast, testicular, colorectal cancer survivors; available to hospital patients
Primary-care medical group	Social worker–led, telephone-based program; survivors also receive mailings and follow-up calls	Licensed clinical social worker	Oncology medical groups contracted to provide services to plan members	Breast cancer survivors; available to member patients

led by a breast surgeon and adult nurse practitioner survivorship team, decided to implement a nurse practitioner–led clinical survivorship program that would offload cancer survivors from the surgical clinics, starting with breast cancer survivors and later expanding to urologic and colorectal cancer survivors. The survivorship team partnered with an existing in-house Avon-funded breast navigation program to share resources and avoid duplication of effort.

A consultative model for the survivorship clinic was initially implemented, in which the bilingual (English/Spanish) nurse practitioner would see post-treatment breast cancer survivors for a comprehensive visit focused on common survivorship issues, including a psychosocial/emotional health screening. However, it was found that the majority of survivors also had unmanaged comorbid conditions and lacked access to primary-care services. Thus the survivorship program expanded to a follow-up model with an initial hour-long consultation and shorter follow-up visits, and the program now offers a broader range of clinical services in addition to survivorship care (eg, cholesterol screening, thyroid exams, diabetes management). As with the other programs, patients are provided with a packet of appropriate survivorship resources and materials, and staff are available for follow-up questions and concerns.

SCPs

As with the survivorship programs, there are common core elements in the SCPs developed and used at each institution, but distinctly different methods of creation and delivery, and different elements are emphasized depending on the patient population, model of survivorship care, and staff resources. For example, at the academic center, the creation and distribution of the SCP is handled entirely by the survivorship team, whereas at the community hospital and the primary-care group, partnerships with other organizations are necessary to complete the SCP. A summarized comparison of the SCPs used at each institution can be seen in Table 2.

Academic center. At the academic center, a comprehensive treatment summary and care plan are provided to each patient seen in the survivorship clinic. The cancer treatment history is prepared in advance on the basis of a medical record abstraction done by the survivorship team. Resource-intensive medical record collection is undertaken by staff, who gather all records related to treatment, including those from outside of the medical center system. The cancer treatment history is then carefully abstracted by the nurse practitioner, who uses a customized template for each disease. The template contains sections for each important domain: treatment history (diagnosis and pathology, chemotherapy, radiation, surgery, hormonal treatment), pertinent conditions and medications, recent screenings, family and social history, current symptom review, recommendations for follow-up care and surveillance, and provider contact information (medical oncologist, surgeon, radiation oncologist, primary care physician, etc).

The care plan document is finalized by the survivorship team after the patient's consultation; the completed document is quite comprehensive and includes information on general health and wellness; psychosocial assessment and recommendations; and evidence-based guidelines for future care when available, such as the ASCO guidelines for breast cancer surveillance. Specific referrals to specialists are included when necessary. The completed document is then sent to the patient and to any clinician that the patient wishes to have it, such as a primary care provider or oncologist; an electronic copy resides in the electronic medical record system for future reference. This SCP covers many facets of cancer survivorship and provides a touchstone for providers at the medical center who are involved in the patient's care.

Community hospital. As mentioned above, not all cancer care takes place at the community hospital, and accessing all treatment records for each patient would be a time-consuming task that the survivorship team felt was inefficient given their resources. A creative solution to creating the SCP was found: the survivorship team developed a patient-directed cancer treat-

Table 2. SCP Components Across Four Health Care Organizations

Organization Type	SCP Completed By	Treatment History Components	Recommendations	Other Components	Received By
Academic medical center	Multidisciplinary survivorship team: oncologist, nurse practitioner, psychologist	Detailed summary of radiation, chemotherapy, surgeries, hormonal treatment	Includes evidence- and/or consensus-based recommendations on cancer surveillance, nutrition and physical activity, and general health	Other pertinent medical conditions and medications, psychosocial assessment and depression screen, nutrition and physical activity recommendations, physician referrals	Patient copy, provider copy (PCP, oncologist, ob/gyn, etc), paper chart, and EMR
Community hospital	Patient, with telephone assistance from survivorship program oncology nurse	General summary of radiation, chemotherapy, surgeries, hormonal treatment	ASCO surveillance recommendations for breast cancer survivors included	Suggested follow-up section for surgeon, oncologist, radiation oncologist, PCP, etc; section on imaging studies	Patient keeps own copy and distributes to oncology care team and primary care
County hospital	Survivorship nurse practitioner	Detailed summary of radiation, chemotherapy, surgeries, hormonal treatment	ASCO surveillance recommendations for breast and colorectal cancer survivors included as appropriate	Emotional distress screen, primary care needs assessment, and intervention as appropriate	Patient copy, copy in paper chart, and copy scanned into EMR (electronic template in progress)
Primary-care medical group	Contracted oncology group physicians and staff, with assistance from survivorship program social worker	Detailed summary of radiation, chemotherapy, surgeries, hormonal treatment	ASCO surveillance recommendations for breast cancer surveillance included	Schedule of follow-up care with in-network providers and contracted oncology group	Scanned into EMR (electronic template in progress) and in oncology group paper chart

Abbreviations: SCP, survivorship care plan; EMR, electronic medical record; PCP, primary care provider; ob/gyn, obstetrician/gynecologist.

ment summary and SCP document that is based on templates from ASCO, Prescription for Living, and the Lance Armstrong Foundation. This template contains lay-language text with fill-in boxes for surgical procedures, chemotherapy, radiation treatment, and hormone therapy, as well as a schedule to be completed for follow-up care with both the oncology team and primary care. This document is mailed to the patient and is discussed with the oncology nurse by telephone. The nurse is able to help patients complete the patient-directed SCP and encourages patients to take the document to their oncology team and primary care physician to review and validate the document and insert a copy in the patient's medical record. An evaluation of the usefulness of the patient-directed care plan is currently underway at the hospital.

A second creative solution for completing SCPs was also implemented at the community hospital: the survivorship team sought out a busy local medical oncology group that shares many cancer patients with the hospital and partnered with them on providing survivorship care and SCPs. Patients shared between the hospital and the oncology group practice are now identified; a nurse champion at the oncology group completes the ASCO treatment SCP document for each patient, and the community hospital provides the mail and telephone intervention to each patient. This is a unique collaboration that allows the community hospital to expand the scope of its survivorship program, and it is a novel way to approach completing such an important component of survivorship care. The goal of the SCP in the community hospital setting is to provide a concise treatment summary and help clarify appropriate surveillance in patient-friendly language.

Primary-care medical group. The medical group also found a novel way to put cancer treatment summaries and SCPs into

practice. As a primary-care practice, the medical group relies on ongoing relationships with contracted oncologists to provide oncology care to its members; the medical group may not have access to the detailed cancer treatment records needed to complete the SCP. Thus, as with the community hospital, a partnership was developed. Interested contracted oncologists met with the survivorship team to develop the partnered survivorship program; a modified ASCO cancer treatment summary and SCP template were adapted by the survivorship team. The templates are partially completed by medical group survivorship staff with demographic information, then sent to the oncology groups for completion by either nurses or physicians. The completed document is then returned to the medical group and scanned into the medical electronic record; it is also stored in the medical record at the oncology group. The SCP is used to facilitate communication between the primary care providers at the medical group and the contracted oncology providers, providing a common document available in both settings.

County hospital. The county hospital survivorship team also adapted the ASCO cancer treatment summary and SCP templates for use in the survivorship clinic, with the addition of some primary-care-focused components to address the needs of this population. The nurse practitioner completes a hard copy of the document on the basis of available records and uses it in the clinical visit as appropriate for counseling and education. A hard copy is given to the patient, and the document is stored in the patient's paper chart, with an electronic copy scanned into the electronic medical records. At the county hospital, the focus of the SCP is patient empowerment and understanding; the survivorship team is continually working to make the document more patient friendly, as many patients have low literacy levels. The SCP can be used to facilitate interinstitutional care

and to assist with care coordination at the surrounding area clinics.

Summary

As the importance of survivorship care continues to be recognized across the nation, the focus on different models of care and uses of the SCP will increase. This qualitative study shows that providing high-quality survivorship care is not a one-size-fits-all model; rather, there are many different methods of delivering survivorship care and SCPs. These four examples of survivorship programs—academic medical center, community hospital, primary-care medical group, and county hospital—show that it is possible to deliver survivorship care in diverse settings given a resourceful and dedicated core team.

The key finding is that these successful survivorship programs have developed and implemented unique types of SCP documents within their organizations: (1) the comprehensive SCP created at the academic center, which is completed by the survivorship team and covers many facets of cancer survivorship; (2) the patient-directed SCP developed at the community hospital, which is completed by the survivor with the assistance of an oncology nurse and focuses on treatment history and appropriate surveillance; (3) the adapted ASCO SCP template used at the primary-care medical group, which is completed via a partnership with outside contracted oncologists and focuses on the treatment history, surveillance, and shared care between oncology and primary care; (4) the adapted and translated ASCO SCP template used at the county hospital, which is completed by the survivorship nurse practitioner and focuses on patient education, post-treatment care, and institutional care coordination. Although the core elements are similar across the organizations, the creation, delivery, and focus vary for each SCP type.

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In conclusion, the SCP document is a flexible tool that can be successfully adapted for use in extremely varied settings, from primary care to hospitals to academic centers, to inform and educate patients and providers alike. As survivorship programs are developed and implemented across the country and worldwide, we will see more variations of the SCP document; further study is needed on evaluation of the effectiveness and impact of SCPs on oncology practice and patient care.

Accepted for publication on October 26, 2010.

Acknowledgment

Supported in part by funding from the Lance Armstrong Foundation and the Breast Cancer Research Foundation.

Presented in abstract form at the National Cancer Institute Cancer Survivorship Research Conference: Recovery and Beyond, Washington, DC, June 17-19, 2010.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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DOI: 10.1200/JOP.2010.000115

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