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Quality of Care and Cancer Survivorship: The Challenge of Implementing the Institute of Medicine Recommendations

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Introduction

Looming before us is a major expansion of the number of individuals diagnosed with cancer, simply by virtue of the aging of the population and the high incidence of cancer as part of the aging process. Maintaining the quality of care for these new patients with cancer will be challenged by an anticipated shortage of health professionals—medical oncologists and nurses—to care for the increased number of newly diagnosed and surviving patients with cancer.¹ Although the National Coalition for Cancer Survivorship and the National Cancer Institute's Office of Cancer Survivorship define survivorship as beginning at the time of diagnosis and extending through death, a recent Institute of Medicine (IOM) report on adult cancer survivors focused on the post-treatment phase of the cancer survivorship continuum.² This phase was described as needing specific attention, especially with regard to coordination and quality of care. In 2004 the National Cancer Policy Board and the IOM established a committee on cancer survivorship to examine issues related to improving care and quality of life.² Early in its deliberations, the committee decided to focus its efforts on describing the quality-of-care needs for patients with cancer who were beyond the acute phase of treatment and living with cancer—and its aftermath—as a chronic disease. The resulting IOM report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,² outlines the key issues facing cancer survivors and makes concrete recommendations as to how to address these problems.

Why is cancer survivor care special? Should not coordination of care between specialist and generalists be expected? Patients with cancer often require treatment by multiple specialists (surgeons, radiation oncologists, medical oncologists) due the use of multimodal therapies and the frequent use of organ-sparing treatments. Chemotherapy administration may require both inpatient and outpatient visits, and radiation therapy may not be given in the same facility where surgery and chemotherapy are received. As a result, there is seldom a single integrated medical record and there may be limited formal (written) communication between the specialists. Primary care providers are often not included in the management of the patient during this time, and it may be months to years after the completion of treatment that the patient returns for regular check-ups with

the primary care provider. In addition, patients may become so focused on the cancer and the potential risk of its recurrence that they may neglect other aspects of their health and have limited follow-up with their regular provider. Adding to this situation is the failure of the oncology care system to provide education and guidance to patients at the end of active cancer treatment—something that is very effective at diagnosis and during treatment—and as a result, the patient often feels lost in transition. Although treatments may be completed, often patients are left with many physical symptoms, which for the most part gradually resolve. Oncology specialists are not always able to predict the time course of recovery, and many patients need a lot of psychological support during this time—something that is not always forthcoming.³ Thus, it is the intensity, complexity, and length of cancer treatment that magnifies the need for coordination of care during the phase of extended survival once cancer treatment is completed.

Cancer survivors face some unique challenges. In the short term, many survivors need to have an understanding of what treatments they received and what kind of follow-up is necessary. This is for their own information, so that they can understand how they can recover effectively, but also so they can tell others (family, friends, employer, other health professionals) what to expect. Often, they have put many activities on hold and look forward to resuming a normal life. During this early post-treatment time, patients need guidance, which is often lacking in the current health care delivery system. They are also eager to have a better understanding of long-term effects of the treatments that need monitoring (eg, cardiac or pulmonary toxicity, second cancers, and so on) and whether other specialists are required. There is a tendency to worry about every ache and pain, and during this time, many scans and tests are likely to be done to look for cancer recurrence, and many additional specialists may be consulted. In addition, there is growing evidence that the psychosocial needs of patients with cancer are unmet as part of routine care, and this situation is often exacerbated at the survivorship care transition.³

What Were the IOM's Recommendations?

The specific recommendations of the IOM report on adult cancer survivors are listed in Table 1. Many of these apply

Table 1. Ten Recommendations of the IOM Report

1	Health care providers, advocates, and other stakeholders should raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.
2	Patients completing primary cancer treatment should be provided with a comprehensive care summary and follow-up plan written by the health care provider(s) who provided cancer treatment.
3	Systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments should be developed to manage late effects of cancer and its treatment.
4	Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.
5	The Centers for Medicare and Medicaid Services, NCI, Agency for Healthcare Research and Quality, the Department of Veterans Affairs, and other quality organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.
6	Congress should support the CDC, the states, and other collaborating institutions in developing comprehensive cancer control plans that include survivorship care. Community-based services and plans generated by public health agencies or public health practitioners are the key to establishing successful disease prevention activities of relevance to cancer survivors.
7	NCI, professional associations, and voluntary organizations should expand and coordinate efforts to provide educational opportunities to health care providers to equip them to address the health care and quality-of-life issues facing cancer survivors.
8	Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.
9	Federal and state policymakers should act to ensure that all cancer survivors have access to adequate and affordable health insurance; insurers and payors of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.
10	NCI and funding agencies as well as private health insurers should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care.

Abbreviations: IOM, Institute of Medicine; CDC, Centers for Disease Control; NCI, National Cancer Institute.

Adapted from Hewitt et al.²

broadly to quality of care for patients with cancer, and also emphasize the need for more research on the late effects of cancer treatments, leading to the development of guidelines for

follow-up care. The first two recommendations are critical for all of these activities, in that recommendation 1 notes the importance of recognizing the largely neglected post-treatment phase of the cancer continuum as a time when better coordination of care among providers and communication with patients could improve the situation. An immediate solution to this problem is recommendation 2, which focuses on the central role and value of the treatment summary and survivorship care plan for all patients who enter this post-treatment phase.

Why do patients need a survivorship care plan?

- To summarize and communicate what transpired during cancer treatment
- To describe known and potential late effects of cancer treatments, with expected time course
- To communicate to the survivor and other health care providers what has been done and what needs to be done in the future
- To promote a healthy lifestyle to prevent recurrence and reduce the risk of other comorbid conditions

Although specific research has not been done to evaluate the impact of treatment summaries and care plans, this recommendation flows directly from other IOM work that has been directed at how the health care system can ensure quality care. This includes the need for promotion of continuous healing relationships; customization of care based on the patient's needs and values; patient-centered care; shared knowledge and free flow of information; evidence-based decision making; safety as a system property; the need for transparency; the anticipation of needs; decrease in waste; and facilitation of cooperation among physicians.² The vast majority of oncology care occurs in the outpatient setting, where summary notes are seldom prepared and initial treatment plans may be altered during the course of treatment. Furthermore, primary care physicians are seldom included in the correspondence during treatment and may not resume seeing patients until many months later. Thus, the IOM report concluded that a summary of the cancer treatment and post-treatment recommendations would facilitate the sharing and coordination of care as patients move forward after completion of primary treatment.

ASCO's Response to the Call for Survivorship Care Plans

ASCO has been actively involved in responding to the IOM report on adult cancer survivors, with special attention to recommendation 2. The IOM report did not dictate what the contents of the survivorship care plan should be, but made some general recommendations (Table 2). In follow-up to the release of the IOM report, ASCO participated in a workshop that focused on the implementation of the care planning recommendation (see Hewitt and Ganz⁴), and subsequently has been active in the development of templates to facilitate development of these summaries for use in practice (see www.asco.org/treatmentsummary), with current versions available for adjuvant therapy of colon cancer and breast cancer, a generic

Table 2. Key Elements of the Survivorship Care Plan

Specific tissue diagnosis and stage
Initial treatment plan and dates of treatment
Toxicities during treatment
Expected short- and long-term effects of RX
Late toxicity monitoring needed
Surveillance for recurrence or second cancer
Who will take responsibility for survivorship care
Psychosocial and vocational needs
Recommended preventive behaviors/interventions

Abbreviation: RX, treatment.

template, and several templates for lung cancer. ASCO has been working with the electronic health record vendors for the last 2 years to have these treatment summaries produced as a regular output from the oncology-specific electronic health record products that they are developing. Finally, this last year, several Quality Oncology Practice Initiative (QOPI) measures have been introduced to document whether oncology practices are providing their patients with treatment summaries. This is all a work in progress, but we are slowly beginning to see this move into the routine practice arena.

What Is Happening in the Comprehensive Cancer Centers?

In 2004, the Lance Armstrong Foundation began to fund Centers of Excellence in National Cancer Institute–designated comprehensive cancers, to develop the LIVESTRONG Centers of Excellence Network.⁵ In 2006, the Jonsson Comprehensive Cancer Center (University of California, Los Angeles [UCLA], Los Angeles, CA) became a part of this network and launched a clinical practice designed to provide consultations for cancer survivors, as part of the UCLA-LIVESTRONG Survivorship Center of Excellence. We established the Vital Information and Tailored Assessment (VITA) Program (www.cancer.ucla.edu). The idea was to provide multidisciplinary survivorship consultations for individuals who had completed cancer treatment, with a focus on recovery and enhancing post-treatment health and well-being. In the last 2 years, we have seen 320 cancer survivors in consultation. Some of these are survivors of childhood cancer, but many are like Mr Feuerstein—the patient who wrote another article in this series⁶—and are either long-term survivors who have been seeking an answer to their persistent post-treatment complaints, or are individuals who have recently completed treatment and want to know how to move into the next phase of their experience as a patient with cancer.

The key to providing these consultations is obtaining past medical records to understand the person's cancer diagnosis and treatment exposures, as well as any complications from the treatment. This is often the most significant barrier to performing a quality consultation, especially if the treatment occurred many years earlier and if the patient does not have copies of the

records; however, it is relatively simple for patients who are from our own institution. Once records are obtained, they must be reviewed and synthesized. In our center at UCLA, this is done by a nurse practitioner who shares the care of the patients. When the record review is completed, and several days before the consultative visit, the nurse presents the case to one of the two physicians involved in the program. At that time we determine whether other information is needed and what the patient's likely concerns might be. This allows us to anticipate whether other specialists might need to see the patient, especially if the patient is coming from out of town.

Before the visit, we have the patient complete a comprehensive questionnaire that delineates any chronic medical and psychosocial problems, as well as family history and outline of symptoms. We also ask the patient to focus on the major problems that are a personal concern and with which he or she would like help. The patient also completes depression screening and nutrition assessment questionnaires. These are used to facilitate the interview. The consultation usually takes about 60 to 120 minutes, depending on its complexity and the needs of the patient. We have had full reimbursement for these consultations, and patients who are in managed care health plans have been able to receive authorization for these visits. They are billed as one would bill any other oncology consultation, but modifying v-codes for "history of..." are used and the diagnoses recorded relate to the complications or late effects of the past treatment.

All patients are seen first by the mental health specialist member of our team, which sets the stage for the remainder of the consultation. For many patients who have otherwise received excellent cancer care, there has never been an opportunity for them to address their emotional concerns or response to the illness. These encounters with our mental health colleague may have a profound effect in terms of focusing the patient on issues they have not considered before. This in itself may be an intervention, but some patients desire additional mental health follow-up, and this is arranged either on a short-term basis or a referral is made. At the completion of this assessment, the mental health provider reports the patient's status to the nurse and physician before making an assessment and recommendations.

The medical component of the visit focuses on the patient's past cancer history and treatment, usually including reassurance about the appropriateness and success of the prior treatment. Nevertheless, any lingering toxicities or questions about treatment can be addressed before discussing specific current concerns and health promotion recommendations. We generally follow the three guiding principles of survivorship care, which include palliation, health promotion, and disease prevention (Table 3). Symptoms associated with cancer treatment, such as pain, fatigue, sexual problems, weight gain, and body image problems, are all amenable to some form of treatment and need to be addressed in a systematic way. Similarly, lack of attention to health promotion (physical activity, diet, bone health, and so on) can detract from survivors' long-term health and quality of

Table 3. Principles of Survivorship Care

Palliation
Medical care or treatment that concentrates on reducing the severity of disease symptoms (particularly if there is not a curative medical treatment)
Goal is to prevent and relieve suffering and to improve QOL for people facing complex illness
Prevention
Early detection and early intervention for potentially serious late-onset complications (eg, cataracts, osteoporosis, and cardiac disease)
Chemoprevention when available
Lifestyle modification to prevent second cancers
Health Promotion
Promote risk reduction for health problems that commonly present during adulthood (especially for childhood cancer survivors)
Avoid weight gain
Increase physical activity
Avoidance of exposures that are harmful (eg, tobacco, sun)
Decrease risk of other chronic diseases (eg, diabetes and heart disease)

Abbreviation: QOL, quality of life.

life. Finally, disease prevention, which includes surveillance for cancer recurrence, screening for other cancers, as well as other chronic diseases, is absolutely essential, given the higher risk of some patients based on their past treatment exposures. We calculate the patient's body mass index; vigorously counsel regarding weight gain prevention, weight loss as appropriate, and regular physical activity; and conduct a detailed dietary interview with counseling using the Rapid Eating and Activity Assessment for Patients questionnaire, an assessment tool designed for primary care office practice.⁷ We also provide tailored written materials relevant to the patient's diagnosis and circumstances. After the in-person consultation, the patient and all of his or her providers receive a detailed written treatment summary and survivorship care plan, which also resides in the medical record.

Although this process is time consuming and is sometimes referred to as boutique medicine, these VITA consultations have been extremely well received by patients and physicians. Our medical group practice sees this as a way of coordinating care for oncology patients at our institution, and we are systematically inviting recently treated patients to have a consultation—without interrupting their ongoing care with their main oncology providers. Primary care physicians have referred patients to us for consultation when they have new patients with a cancer diagnosis in the distant past—these consultations help them and their patients learn where they stand and what needs to be done. Finally, many patients who have been fending for themselves for a long time, like Mr Feuerstein, find us and are greatly relieved to have someone listen to their story and acknowledge their concerns and needs. For most of these longer term survi-

vors, the consultation is truly a teachable moment, and can be a dramatic and life-changing catalyst for the assumption of better health habits and improvements in emotional well-being. It is exciting to be a part of this effort and to see the transformative nature of the encounter.

Each of the centers in the LIVESTRONG Survivorship Centers of Excellence Network⁵ have developed slightly different models of care, which fit the specific needs of their comprehensive cancer centers. What is most important is that they are serving as centers for innovation, education, and model development—particularly because all of them have community-based affiliates. Most of these centers also have an evaluative component, so that over time we will learn more about the cost and effectiveness of the various strategies for delivering survivorship care. Almost all are dependent on a combination of fee-for-service funding, research, philanthropy, and institutional support to deliver care to patients with complex needs. The delivery of this type of care within an oncology practice should be much simpler, given that the patients are known to the office staff; obtaining information from the medical record should be straightforward—especially if done in a timely manner—and the services that are provided (eg, palliative care, psychosocial services) should be an integral part of acute oncology care.

One Size Will Not Fit All

Evidence-based support of the effectiveness and the cost benefit of this approach will be necessary to reach the level of certainty needed for wide-scale adoption of the cancer survivorship care plans and the associated consultations. Many different models for delivery of survivorship care plans are emerging, and there will not be a one-size-fits-all solution. The current health care delivery system has neglected the post-treatment phase of the cancer continuum. To enhance the medical outcomes of these individuals (disease-free and overall survival), we must now pay attention to management of the long-term and late effects that are often associated with successful cancer treatment. Oncology is winning the war on cancer. Patients are living longer. However, this does translate into a growing number of people who need a different type of care. This presents both an opportunity and a challenge to the delivery of cancer care services.

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INTRODUCING ASCO'S NEW SOCIAL NETWORKING WEB SITE

ASCO has developed a new social networking Web site, *Oncology EHR: Quality and Safety*—where different oncologists can connect and share information about the use of Electronic Health Records (EHRs) in oncology practices. This new social networking Web site serves as a platform for oncologists and different vendors of EHRs to discuss the advancements, usability, and challenges that emerge in using EHRs in oncology offices. In addition to blogging, users can build up their personal profile page and incorporate widgets and RSS feeds on their page as well. Users have already begun posting invites to EHR-related events such as EHR Web casts, EHR Lab at the Annual ASCO meeting, and other EHR symposiums to be held at ASCO throughout the year. Become a member today! Visit <http://ehr.ascoexchange.org> to sign up.

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