

# Cancer Quality Alliance Proceedings

## Cancer Care and Survivorship Planning: Promises and Challenges

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### Introduction

At the September 2008 Cancer Quality Alliance meeting, and throughout this Special Series of articles, various stakeholders have highlighted the promise of improved cancer treatment and survivorship planning. It is worth reiterating that much of the need for survivorship planning is a sign of medicine's success. Improvements in early detection and treatment have resulted in a substantial increase in the number of cancer survivors. Data from the National Cancer Institute suggest that in 1972 there were approximately 3 million cancer survivors alive in the United States.<sup>1</sup> In 2005, that number approached 11 million; in 2008, the number exceeded 12 million.<sup>1(p18)</sup>

Recent studies report that the incidence and death rates of several major cancers are declining in both men and women. However, with an increasingly aging and enlarging population, the United States is likely to see a continued increase in the number of people living with cancer for the foreseeable future. ASCO has estimated that from 2000 through 2020, the United States will see an overall 40% increase in the cancer incidence among women, and a 55% overall increase in the incidence of cancer in men.<sup>2,3</sup>

The good news is that we now have a substantial cancer survivor community that has lived many years after primary treatment. However, that is a relatively new phenomenon. For example, in 1976, 50% of cancer patients survived 5 years after diagnosis. Today, that number is approaching 67%.<sup>4</sup> The not-so-good news is that although we have made some progress in understanding long-term effects of some cancer treatments, there is still much more we have to learn about the impact of our treatments on our patients.

### Role of Primary Care in Cancer Survivorship

These statistics underlie another significant challenge. At the same time we can expect to see an increase in the demand for oncology services, ASCO has projected that we are going to see a significantly lagging supply of oncologists available to treat those patients.<sup>4</sup>

As a result, we can anticipate that there will be significant changes in the way we treat patients with cancer. It is probable that follow-up care for cancer survivors will be handled more

and more by primary care physicians, nurse practitioners, and physicians' assistants, among other health care professional groups. Such options are not without their own issues, including a rapidly declining number of medical students and young physicians willing to pursue a career in primary care internal medicine or family practice. Workload, lifestyle, and poor compensation relative to other medical specialties are cited as factors exacerbating this disturbing shift in the medical workforce.<sup>5</sup>

To make primary care a more attractive career choice and enable primary care medical practices to offer a more comprehensive spectrum of quality medical care, efforts are currently underway to revamp the way we provide primary care services. One model that is currently receiving a substantial amount of attention is the Patient Centered Medical Home. Designed to be a more inclusive, holistic approach to primary medical care, this model will use advanced practice nurses and other physician extenders to provide care and education for patients. It will also rely more extensively on electronic medical records to bridge patient care and knowledge gaps, and enable health care professionals to apply current medical guidelines and information in real-time at the point of service.<sup>6</sup>

### Survivor Care Plans: Opportunities and Obstacles

Given that these fundamental alterations in the medical care landscape are happening, and in an effort to address significant gaps in the medical care system for current patients who have been treated for cancer, the Institute of Medicine (IOM) published a landmark report in 2006 entitled "From Cancer Patient to Cancer Survivor: Lost in Transition."<sup>7</sup> This report, which remains the pre-eminent document in this field, has been reviewed in detail in other articles in this series.<sup>8</sup>

A follow-up report was published in 2007 by the IOM in collaboration with the National Coalition for Cancer Survivorship, The Lance Armstrong Foundation, and the National Cancer Institute. Entitled "Implementing Cancer Survivorship Care Planning,"<sup>9</sup> the report summarized the proceedings of a symposium held to address some of the questions raised by the initial 2006 report.

The symposium examined fundamental issues related to effective implementation of cancer survivorship care plans, including:

- What are the essential elements of the care plan? Will a single template work?
- Who is responsible for creating the plan and discussing the plan with patients?
- What are the respective roles of oncology/primary care and physicians/nurses?
- What economic strategies could encourage implementation of care planning?
- What barriers exist to creating the care plan? How can they be overcome?

Unfortunately, as we revisit this issue today, there remain a number of obstacles to implementing survivor care plans. The first obstacle is the inconsistent evidence base for cancer survivorship care. There has been progress in the pediatric cancer population with respect to providing evidence-based recommendations for advancing cancer survivors' medical and psychological care (which are discussed by Horowitz et al<sup>10</sup> in a separate article in this Special Series). For adults, however, the evidence base on which we support our advice and recommendations regarding long-term effects of cancer treatment for our adult cancer survivors is largely lacking. Whereas children are generally treated according to specific protocols in specialized cancer centers, and are observed carefully by those centers for many years, much of adult cancer treatment is fragmented in many different settings without adequate data collection and long-term follow-up in a single facility or physician's office.

There is general agreement that we need to make a substantial investment to develop this knowledge base. As highlighted by the IOM reports, we should not wait for this evidence base to improve our communication with our patients regarding their survivorship care needs. Until the research-based evidence exists, we have to rely to a considerable degree on expert opinion and consensus to answer our patients' questions about survivorship and define their special needs after they complete their treatment.

According to some experts, systematic documentation of planning is a process that should begin when treatment starts, not when it is completed. By creating a dialog and a partnership with a patient, the oncologist has the opportunity to create an open and caring environment from the beginning of treatment. The treatment care plan can become the introduction to that discussion and be updated during the course of treatment as circumstances warrant.

We need to recognize as a profession that these plans serve many needs for patients, their caregivers, other physicians, and even researchers. By providing a resource that concisely states the type and stage of a cancer, the planned and implemented treatment plan, and a summary of future needs and expectations, our patients will inevitably become more informed about their care.

## Role of Health Information Technology

There is considerable hope that health information technology is going to bridge many gaps in our health care system. However, existing medical records, for the most part, are not adequate for research or information purposes. We do not have an adequate, straightforward way to advise our patients what they can expect after they leave the care of their oncologist and return to the general medical community. We also lack the tools we need to inform our primary care colleagues and other health care professionals of current research and the information they need to address the medical care of cancer survivors.

Some organizations, such as ASCO, have already developed and promoted model survivorship plan templates both for selected cancers as well as a generic form. These are available on the ASCO Web site at [www.asco.org/treatmentsummary](http://www.asco.org/treatmentsummary), and can be modified to suit individual needs and expectations. Although these documents move us several steps closer, oncology has not widely accepted or implemented a standard document for a survivor care plan. Absent such agreement, it is unlikely that survivor care plans will soon get the traction in the cancer community that they deserve.

Additional challenges to care and survivorship planning include the need to keep the information up to date as additional research becomes available, such as genetic/familial implications for specific cancers or newly discovered long-term complications of cancer treatment. Several practical questions emerge: who will maintain storage of the patient-specific information, and how will we contact the patient when that new information becomes available? How can we provide the resources necessary to maintain contact with the patient and offer him or her not only up-to-date credible survivor information, but also the opportunity to participate in clinical trials as appropriate?

All of these activities require financial and human resources to be effective. In these days of limited budgets and other similar constraints, the difficulties become obvious.

Other observers have noted that patients and their families have not been demanding this information. As patients transition into survivorship after cancer treatment and as they become longer term survivors, other more common medical problems tend to take precedence in patient care. Repeated efforts to engage patients and others in developing online personal health records have been only marginally successful, despite the clear and demonstrated value of a medical record summary available on demand, especially when a new physician is involved or in times of emergency care.

Making cancer treatment and survivorship care information readily available to both patients and their treating physicians in an easy, seamless manner is critically important to the overall medical management of our cancer survivors. Health information technology offers great hope, but until the data elements conform to common standards, can be communicated from

oncologist to primary care physician routinely and easily, placed in the appropriate format of the primary care physician's electronic medical record, and provide point-of-service information specific to the care of that patient, we will not have achieved our goal. Most experts in the area of survivorship recognize that we must come to grips with these issues if we are going to broaden the appeal and the effectiveness of survivorship care plans. We need to have some agreement as to what information is most important for patients and their families, as well as other treating physicians and health care professionals. We must find a way to minimize the disruption of creating and maintaining these forms. Oncology-specific data standards for electronic medical records along with a uniform report format, supplemented by standard evidence-based recommendations, would go a long way to increasing uptake of this concept.

## Conclusion

Providing reasonable reimbursement for completion of the treatment and survivorship planning forms, as well as consultative time to meet with the patient and caregivers, would also aid uptake. We need to recognize that these survivor care plans are not an end to themselves, but merely an introduction to a conversation that must take place. They are a valuable part of

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oncology care and deserve to be recognized as such by payors and others.

For the future, we need to increase our commitment to research that identifies the continuing needs of our patients, as well as the complications of our treatments. We will need to develop tools for other health care professionals to use as the care of cancer survivors moves more and more into the community setting. If we fail to meet this challenge, then we will find ourselves curing cancers, but inevitably sending our patients out into the community with far fewer tools than they need for their long-term journey as survivors of their diseases.

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### Author's Disclosures of Potential Conflicts of Interest

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