

From Cancer Patient to Cancer Survivor: Lost in Translation

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As a 20-plus-year cancer survivor, I have been heartened to see the number of cancer survivors increase (currently estimated at well over 10 million Americans), and new attention paid to the unique, wide-ranging, and long-term issues that follow the diagnosis and treatment of cancer. This volume reflects that trend. It reports the work of an Institute of Medicine (IOM) and National Research Council (NRC) of the National Academies "Committee on Cancer Survivorship: Improving Care and Quality of Life."

The committee consisted of a diverse group of 17 individuals from academia, not-for-profit health advocacy organizations, as well as health-care providers; its deliberations took place between July 2004 and March 2005. The stated goals of the work were to:

- (1) raise awareness of medical, functional, and psychosocial consequences of cancer and its treatment; (2) define quality health care for cancer survivors and identify strategies to achieve it; and (3) improve the quality of life of cancer survivors through policies to ensure their access to psychosocial services, fair employment practices and health insurance.

The book discusses the difficulties associated with defining cancer survivorship. Here, the committee and editors chose to focus on adults who completed primary treatment for cancer and had no recurrences. This leaves out survivors of childhood cancers, who were discussed in another IOM report (*Childhood Cancer Survivorship: Improving Care and Quality of Life*, 2003), as well as end-of-life cancer care, which also was covered in an earlier IOM report (*Improving Palliative Care: We Can Take Better Care of People With Cancer*, 2003). Although cancer survivors with chronic or intermittently treated cancers are not directly addressed, the recommendations of the current volume are also of relevance to them.

The committee took advantage of a plethora of available, but not necessarily integrated, sources of data. The resulting book is a valuable reference. Several chapters present descriptive data about cancer survivors, and the ways in which their lives are affected by a cancer diagnosis and its treatment. This coverage is quite broad, including discussion of physical, psychosocial, vocational, spiritual, and economic issues. It should be useful to patients, their advocates, and health-care providers. Several other chapters focus on defining optimal care for cancer survivors—both medical and psychosocial—as well as describing models for delivery. These chapters should be of interest to health-care providers, health advocates, and policy makers.

Recommendations

The committee's 10 recommendations are summarized below:

- (1) Increase *awareness* of the physical and psychosocial issues associated with cancer survivorship.
- (2) Provide written "*survivorship care plans*" at the completion of primary cancer treatment.
- (3) Base care of cancer survivors on *evidence-based practice guidelines*.

(4) Use *quality assurance measures* to monitor and continuously improve care of cancer survivors.

(5) Implement *demonstration programs* to test approaches to coordinated, interdisciplinary care of cancer survivors.

(6) Incorporate cancer survivorship care into *comprehensive state cancer control plans*.

(7) *Educate health-care providers concerning* issues facing cancer survivors.

(8) *Eliminate employment discrimination* that affects cancer survivors.

(9) Ensure access to adequate and affordable *health-care insurance* that covers survivor care.

(10) Increase *survivorship research*.

Discussion

Almost all cancer survivors are willing to pay the often considerable costs required to become cancer survivors—certainly I was. Still, that doesn't diminish the need to recognize and more effectively deal with these costs. The attention this volume gives to the long-term physical consequences of a cancer diagnosis and treatment will help patients and their caregivers to better treat them. These consequences include disfigurement and loss of function from surgery—for example, impotence and incontinence among prostate cancer survivors; lymphedema and limited arm mobility and sensation in breast cancer survivors; and loss of bowel function in colon cancer survivors; as well as chronic fatigue, neuropathy, reproductive difficulties, and cognitive impairment among many cancer survivors who have undergone radiation or chemotherapy.

Likewise, the volume's clarification of and strategies for dealing with long-term psychosocial issues will help ameliorate them. These include fear associated with cancer recurrence, secondary cancers and a plethora of other

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comorbidities, as well as spiritual, employment, and economic issues.

Ancillary health professionals (eg, social workers, oncology nurses, cancer center administrators, networks of health-care providers, and payers) are especially likely to profit from the book. They, as well as cancer advocates, will find their outreach and advocacy agendas refined by the information and suggestions provided. Indeed, this is already occurring. For example, several cancer advocacy organizations are working to bring “cancer survivorship plans” into standard clinical practice. Likewise, there is increased effort directed at educating health-care providers and the general public about survivorship issues. Also, the use of quality metrics and continuous improvement is gaining momentum in health care in general, including in cancer survivorship (see examples at www.ahrq.gov and www.cms.hhs.gov/HomeHealthQualityInits).

Because cancer survivorship must

be dealt with in the context of a health-care system in crisis, some of the recommendations made in this volume are really a vision for health policy change in general (eg, evidence-based medicine, universal access). These are certainly worthy recommendations, but it is unlikely that the book will have a significant impact on overall health-care policy. Such changes are being debated along state and economic lines, rather than on a disease-by-disease basis. Also, while a case could be made that every general practice physician could profit from reading this book, it is unlikely that many will.

The more specific goal of this volume—to advance awareness of issues facing cancer survivors—is excellently accomplished. I hope reading it leaves others, as it did me, even more committed to redoubling efforts to deal with these issues. Although “first do no harm” is a hallmark of medicine, it is clear that considerable harm

is done in the interest of extending the lives of those diagnosed with cancer. Yet, by some estimates, at least 30% of people diagnosed with breast and prostate cancer (who constitute approximately 40% of cancer survivors) would have lived natural lives and died of other causes had their cancers never been diagnosed or treated. We must do better at identifying individuals who do not need to be diagnosed or treated, and hence never need to suffer the consequences of cancer. In addition, we know that only a minority of patients who are given most therapies are actually helped by them, although most suffer some harm. We must do better at identifying which treatments will work for which individuals. This goal of personalized cancer treatment is on the horizon but not yet a reality. In the meantime, the ranks of cancer survivors will increase, and this volume will help improve their care and quality of life.

—Jane Perlmutter, PhD

This month in

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oncology NEWS INTERNATIONAL

Breaking News From ASCO 2006

■ ATLANTA—See *ONI* June for the major stories coming out of this year’s annual meeting of the American Society of Clinical Oncology. Also, watch for comprehensive coverage of the meeting in the July issue. Breaking stories will include reports on lapatinib (Tykerb) plus capecitabine (Xeloda) in breast cancer, and targeted therapy with sunitinib malate (Sutent) and temsirolimus in renal cell carcinoma (see *ONI* June, pages 1 and 2).

Thalidomide Has ‘Changed the Paradigm’ in Myeloma Therapy

■ HOLLYWOOD, Florida—Thalidomide has “changed the paradigm” for treating multiple myeloma, and advances in understanding the relationship between myeloma cells and the bone marrow microenvironment promise to change it even more, Kenneth C. Anderson,

MD, of the Dana-Farber Cancer Institute, said at the National Comprehensive Cancer Network (NCCN) 11th Annual Conference. (see *ONI* June, page 17).

FDA Approves Dacogen for All MDS Subtypes

■ ROCKVILLE, Maryland—The Food and Drug Administration (FDA) has approved the marketing of Dacogen (decitabine for injection, MGI Pharma) for the treatment of all forms of myelodysplastic syndromes. The agency acted after reviewing data submitted by the sponsor from a pivotal phase III trial, in which patients evaluable for response had a 21% overall response rate, and two supporting studies (see *ONI* June, page 18).

And in this month’s Cancer Care & Economics: Universal Health Care Voucher System Could Be a Solution to US Health Care Financing Dilemma.