Michael Feuerstein
Patricia A. Ganz *Editors*

Health Services for Cancer Survivors

Practice, Policy and Research

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Preface

Introduction

Now What?

The question many cancer patients have when primary treatment for their cancer is over is … now what? They often ask, "Do I just try to cope with a 'new normal' that my doctors and nurses talk about? Do I deal with each problem that I now confront on my own so I can move forward in my recovery? Do I need some type of different health care now that I have been diagnosed and treated for cancer? How can I stay healthy even with my new medical history?" Over the past decade, efforts to improve the health of cancer survivors have moved at lightning speed. This book was conceptualized and assembled to provide a comprehensive review of this progress, as well as to lay the foundation for future improvements in survivorship care.

This book follows the complementary publications of *Cancer Survivorship: Today and Tomorrow* [1] and *The Handbook of Cancer Survivorship* [2] both published in 2007. Those two volumes, edited by Drs. Ganz and Feuerstein respectively, were published to provide those involved in the daily care of cancer survivors, health care researchers, and survivors themselves, timely information on specific long-term and late effects associated with cancer survivorship. They also informed readers of the recent knowledge regarding research and practice in both the medical and nonmedical dimensions of cancer survivorship. However, an important question that was not addressed by either of those volumes is how do we translate the information on cancer survivorship into efforts to provide "quality care" for cancer survivors?

Conventional wisdom is that health care for the cancer survivor is really not very different than for any other chronic illnesses. The survivor needs to receive surveillance for cancer recurrence usually by oncology, routine physical exams and preventive services from primary care, as well as health promotion advice focused on physical activity, weight, and stress management. There is an assumption that all of these things will fall into place during the posttreatment period, and that everyone on the health care team as well as the survivor knows the drill. However, this is not always the case, and what is more problematic, the chaotic way in which posttreatment care occurs raises the question, should delivery of the cancer survivor's long-term health care be more pro-active and comprehensive with a more personalized prescription?

The increasing number of cancer survivors populating the practices of many oncology specialists and primary care providers is raising practical questions about how to provide the best quality care in our still fragmented health care system. Although guidelines are emerging, currently high-quality evidence for many recommendations of care is limited, with wide use of consensus and expert opinion.

This book was written to help fill the current gap in knowledge dissemination related to quality care for cancer survivors. For example, a recent survey of primary care providers indicated that they want to provide meaningful care to patients who are survivors of cancer, but because of a lack of training expressed concern with doing so [3]. As the number of cancer survivors in the USA and around the world increases exponentially and as the world population ages at the current rate, there is every reason to predict a major upsurge in both the incidence and prevalence of all types of cancers [4]. To respond to this major public health challenge, bold steps to improve the breadth and depth of knowledge and skills of those who can provide quality health care to cancer survivors across their lifespan must be a priority. This book represents an effort to help achieve that.

To put this into perspective, let us reflect on the personal experience of one of us (MF). MF has lived through the flurry of aggressive cancer treatments. Understandably at the time of diagnosis, neither concerned nor aware of long-term or late effects, survival was the priority. It was only after M completion of radiation treatment and a few months of chemotherapy that his RI indicated that the primary brain tumor was not visible that his focus shifted to the persistent symptoms resulting from treatment, new health concerns, functional loss, and distress. The cancer diagnosis was anaplastic astrocytoma, an inoperable cancer of the glial cells in the brain. The prognosis was not good. He was 52. Following resection to confirm the neuropathology, 59 Gy of cranial radiation and 12 months of chemotherapy, he was informed by the neuro-oncology group that things looked good for now and that there was nothing else to do with the exception of routine surveillance. These visits were critical to detect when or if the brain tumor returned. With a very genuine and positive intent, he was told to "Go and enjoy life." He was on his own now with his wife, family, and friends. His primary care physician, while very competent, commented that the best way to manage his health now is to proceed just as we would without a history of cancer.

Dr. Feuerstein describes his experience, which is not unique, as follows:

At the prime of life I was confronted with this new challenge. I wanted to return to my life as it was prior to diagnosis. After all, I was only 52. I began searching for solutions to various problems that I now experienced … unimaginable fatigue, memory and organizational difficulties, weight gain, hearing loss, low levels of activity, problems at work because of the diagnosis of cancer, and an intense fear that the aggressive tumor would return as a stage four glioblastoma multiforme (GBM), which I was told can frequently happen. The last thing I wanted was to be the manager of my own care. For some reason, even I thought that after a diagnosis of such a serious illness that there would be someone like Dr. Marcus Welby (the well-known television character who in his fatherly way knew just how to manage all his patients' health and emotional problems) who would doctor me back to health and help me forever! Well, of course, this did not happen nor was it realistic. I did think there must be a better way.

A few years after my treatment, I ran across the report by the Institute of Medicine (IOM), *From Cancer Patient to Cancer Survivor* [5] that indeed laid out a better solution! The recommendations in this book, consistent with the IOM's position on quality health published a few years earlier [6], indicated that my experience was not that unusual. In the IOM report on adult cancer survivors, whose committee includes many of the authors of chapters in this book, the problems in transitioning from a cancer patient to a cancer survivor were described with provision of some simple but profound solutions. Over the 5 years since that report, many researchers and clinicians have been busy developing additional knowledge and potential solutions regarding the long-term and late effects of cancer treatment, and detection and management of these problems from a biopsychosocial perspective [7]. Their focus has been on creating and implementing new approaches to address the many challenges cancer survivors and the health care system face. This was very consistent with how I as a clinical psychologist learned to treat patients with chronic pain, disability, and chronic illness in general, with a focus on chronic disease and functional restoration. My work as Director of Behavioral Medicine Services at the University of Rochester Medical Center, Division of Behavioral and Psychosocial Medicine (created by Dr. George Engel), along with my interactions with George Engel, Bob Ader, and many pioneers of the emerging research and practice of biopsychosocial medicine gave me a greater appreciation of the role of psychosocial factors in all types of diseases. This experience provided me with the necessary knowledge to begin my efforts to improve the quality of my cancer survivorship care [8].

I met Dr. Patricia Ganz after the publication of the IOM report in 2007. Dr. Ganz, a pioneer in providing quality care for cancer survivors, and her staff at UCLA were kind enough to complete a Cancer Survivor Care Plan for me. I am not a fan of anecdotes or testimonials so let us call this a case study! The bottom line is that this approach helped me to manage and "palliate" symptoms that I thought by this time after treatment I just needed to accept. It provided the comprehensive perspective as a cancer survivor that I knew I needed. While we cannot overstate the potential of just having a personalized "plan" completed, at this point in the evolution of cancer survivor care it is an important element for setting the stage to receive quality health care in a coordinated and comprehensive manner. Although it awaits empirical support [9], it was a systematic process that helped me recalibrate my trajectory forward. As my challenges become more evident to me, it has been clear to me that I needed something like this [10]. Since that time, Dr. Ganz and I have developed a professional relationship and this book has evolved from that experience.

Dr. Ganz comments, reflecting on her more than 30 years as a medical oncologist and as a founding member of the National Coalition for Cancer Survivorship (NCCS) in 1986: I began my first academic appointment in 1978 on the faculty at UCLA at an affiliated VA hospital where I was given an opportunity to establish an oncology ward that would serve the rehabilitation and palliative care needs of our patients. This was a blessing in disguise, for while the world of medicine was just beginning to embrace the earliest British versions of hospice and Elizabeth Kubler

Ross's treatise on death and dying, I had an opportunity to realize that palliative care was something valuable to all patients with cancer from the time of diagnosis until death. Unfortunately, many of the veterans whom I treated suffered from advanced forms of cancer that were not curable, but for some, we achieved long-term durable remissions, and we included a focus on rehabilitation, pain and symptom control, nutrition, and psychosocial support as an integral part of their care. Because patients were often hospitalized for the 6-week duration of radiation at that time, the support staff and nurses all got to know the patients and their families well and were attentive to a robust set of rehabilitation needs.

I was also fortunate in these early years to begin working with a psychiatrist and psychologist (Dr. Coscarelli continues to collaborate with me clinically and contributes an important chapter to this book) on a research project that focused on understanding the day-to-day needs of cancer patients and took a behaviorally based approach to potential intervention. If we did not understand the problems facing the patient, how could we help them cope? This early work formed the basis of a decade or more of research that we conducted developing tools and interventions to measure patient-reported quality of life, as well as the testing of rehabilitation interventions to improve the outcomes for newly diagnosed cancer patients who were expected to have good long-term survival. When I was contacted by Dr. Fitzhugh Mullan to join a small group of people in Albuquerque, New Mexico, in 1986, to discuss issues related to cancer survivorship, I was ready and able to join the adventure, investing my $100 towards the birth of a new organization, The National Coalition for Cancer Survivorship (NCCS).

Over the years, working as a clinician, but more recently largely focused on research, I have had an incredible opportunity to see the mission and vision of the NCCS realized and to have played an active part in that evolution of events. Participating as a member of the IOM committee that prepared the 2005 report on adult cancer survivors, as well as working very hard these past 5 years to implement its recommendations, has given me pause to realize how challenging it is to produce change in the health care system. Even when we have an evidence-based therapy – something like beta blockers that were found to be life saving after heart attacks – dissemination and institutionalization of such therapies may take one to two decades. Implementing survivorship care and survivorship care plans is still in the steep part of the dissemination curve.

In 2006, with funding from the Lance Armstrong Foundation, we were fortunate to be able to establish a Survivorship Center of Excellence at UCLA's Jonsson Comprehensive Cancer Center, where I have worked for the past two decades. This infrastructure grant has allowed us to develop several models for delivery of survivorship care in the Los Angeles region and to work to serve the patients who come for care either at UCLA or our affiliated community sites. We focus on improving the quality of care for cancer survivors – a major goal of this book – and are serving as a laboratory to develop and refine strategies that will work and can be used in other communities. Using a palliative care approach has served us well in these settings and continues to remind me that I have not strayed very far from the medical practice I engaged in early in my career, expect now the vast majority of patients we treat are long-term survivors, and the need to organize high-quality care for these individuals is even greater. Our cancer therapies are more complex, longer in duration, and sometimes more toxic, and we still do not have all the evidence for definitive guidelines for survivorship care. However, this should not stop us from moving forward with a focus on improving the quality of care for survivors, but this is a work in progress.

Organization of Book

Quality Health Care for Cancer Survivors is divided into four broad parts. In Part I of the book, authors provide systematic discussions of the problems faced by cancer survivors in the search for quality care and just what quality care for cancer survivors might look like. Following these introductory chapters, Part II covers areas that if present in a cancer survivor need to be targeted in a coordinated effort to improve a number of outcomes related to health, function, and well-being. The identification of current and potential future problems represents an important aspect of quality care. This procedure referred to as the Cancer Survivorship Care Plan (CSCP) provides an opportunity to do just that and has the potential to integrate care for cancer survivors and serve as a first step. The challenge of managing the many symptoms and problem areas identified in the CSCP, which can present barriers to recovery over time, is discussed along with the need to initiate and maintain healthy lifestyles, optimize function and well-being, and the need to identify and respond to disparities in health care and outcomes.

Part III provides examples of current efforts in primary care, oncology, medical center, and community settings. A chapter that covers Survivorship Clinics, a recently developed approach to survivorship health care that provides innovative clinical practice and research on its outcomes [11], is also included. The final chapter in this section covers end-of-life care, a topic that is often not considered within the context of cancer survivorship. It is cogently argued that despite this lack of attention in the cancer survivorship literature, quality care demands better integration of end-of-life care into comprehensive survivorship care. More research and clinical efforts to better understand and attend to this element of survivorship are critical. It is time that this area of care is more seriously considered.

Part IV provides reviews of basic areas in health services and operations research and development that the editors think may prove important to attend to when working toward creating and implementing innovative approaches to quality health care in cancer survivors. Quality efforts must be sensitive to the epidemiology of cancer survivorship, especially as it relates to major events such as recurrent and new cancers and comorbidities. Health economics enters into all decisions impacting quality care, and a primer of topics in this area is provided to better understand the various approaches used to consider whether or not a new treatment is broadly effective and justifies implementation. A professor of health services in a course one of us took years ago quotes the following when discussing quality care: “We are all looking for Mercedes Benz care with a Ford price tag.”

Even if the new health care reform in the USA impacts disparities related to access and outcomes, the chapter on health disparities is an important reminder that quality cancer survivor care is something we need to achieve for us all. Design and redesign of systems are also often very complicated to achieve. The editors thought that readers could benefit from a consideration of the field of human factors not well known by those involved in cancer research and practice, but a viable field to improve the performance of complex systems. It is hoped that an introduction to its unique "operational engineering" perspective within the context of humans working in complex health care environments may provide innovative technology and insights to help generate improvements in systems of care for cancer survivors.

This book represents the expertise and wisdom of a wide range of specialists. The comprehensive coverage provides the reader with the clear message that quality of care in cancer survivorship is needed now and involves many different specialties. Medicine, nursing, and other health providers and colleagues in many related fields can provide the perspective and knowledge to create an integrative approach to care. Many practice models from the academic medical centers to community hospitals to solo or group practices must be involved.

The chapters in this book highlight challenges as well as identify potential solutions that will require a stronger evidence base to substantiate. However, waiting for these data is not an option. Action must be taken. The day-to-day lives of millions are very much impacted by our actions in this area. As these chapters indicate, additional evidence must be accumulated to better inform the quality of our efforts. However, at present there are hundreds of thousands of experienced providers whose expertise can be brought to bear on this problem. These resources should be set into play NOW.

All authors of this book are active and authoritative researchers and/or practitioners in the areas they write about. They were selected to provide a firsthand perspective on the relevant literature and the application of this knowledge to elements of quality cancer survivorship care. While this book is structured to move through chapters serially, each chapter can stand on its own as a reference for that given area. Although there is some redundancy of references and themes in certain chapters, this overlap was intentional because at this point in time many of these references are seminal in setting the stage for innovation in a number of areas of quality long-term care (e.g., the 2005 IOM report on cancer survivors).

This book also contains a timely chapter on the newly created health care reform in the USA in 2010 and considers its implications for cancer survivors. This in-depth analysis provides a window into opportunities for improving the quality of care cancer survivors now receive in the USA. It should also be of interest to our international colleagues who are working to improve the health care of cancer survivors in their respective countries. In the final chapter, Drs. Feuerstein and Ganz provide some thoughts regarding lessons learned from approaches to chronic illnesses in areas other than cancer that appear to be applicable to cancer survivorship care over the long run. These elements of chronic care need to be tailored to individual cancer survivors. Over two decades of research and practice related to non cancer chronic illness can provide us with useful information for guiding integration of elements of cancer survivorship health care within primary care.

It is abundantly clear that cancer survivor health care needs reform. Many cancer survivors go along with "care as usual" and do the best they can. Given the current and expected numbers of cases, it is essential that cancer survivors receive a level of quality health care that provides the necessary elements to optimize health, function, and well-being over the long term and is fiscally responsive. This care should be comprehensive, integrated, evidence-based, and tailored to cancer survivors with their unique history of exposures and resultant long-term and late effects.

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We also would like to thank all the authors of the chapters in *Quality Care for Cancer Survivors*. Their names are in the list of contributors. Each author worked very hard to get this project done within a year despite their busy clinical and research schedules. For this effort of kindness we are all grateful. We have pulled together the best and brightest in their respective areas to provide a thoughtful and scientifically sound perspective on quality health care for cancer survivors. This information will be invaluable to transform health care for cancer survivors to the level that we all expect as providers, cancer survivors, families, caregivers, health care administrators, and policy makers.

I also want to thank my family for providing me with the love and support to complete projects such as this. My wife Shelly; children Sara, Andrew, and Erica; son-in-law Umang; my grandchildren Kiran, Maya,and Zain; brother David; and mother Shirley have all been a major source of energy and inspiration for me to just "keep on ticking." My father Irving S. Feuerstein will always be a guiding light.

I must also thank all of the other cancer survivors who have discussed with me the many challenges that they have had day in and day out following primary treatment. This, above all, gives me the drive to keep focused in any way I can to improve the health care we access in order to optimize function and well-being.

Also, I want to thank Bill Tucker and Janice Stern, editors at Springer, who have supported my efforts in cancer survivorship over the last 6 years. They helped launch the *Journal of Cancer Survivorship: Research and Practice* and the books related to various aspects of cancer survivorship that were generated in the last few years, including this one. Both Bill and Janice have become strong advocates for cancer survivors, and we all owe them a debt of gratitude for keeping this effort going.

I also want to recognize the assistance we have received from Gina L. Bruns, Briana L. Todd, and Michal C. Moskowitz throughout this project. Their thoughtful input and practical help on many aspects of this project provided the support that is so essential when creating such a volume. Thank you.

Michael Feuerstein, Ph.D., M.P.H.

Mike Feuerstein is a hard act to follow! I cannot imagine what he must have been like before cancer entered his life. He is the consummate multitasker who has made this book happen, with me coming along for the ride. So, I am grateful for having had the opportunity to develop this close professional relationship with him through coediting this book. He is an exceptional cancer survivor who is really making a difference. His drive and creativity are woven throughout the book, especially in the chapters in which he threw people together to work on a topic, where they had differing points of view and would not have considered working together. I think the product is quite novel.

As for me, I am grateful for all of the people in my life who have been so supportive over the years, helping me to carve out an atypical career as an oncology professional and researcher, and allowing me to work towards a vision of better quality care for cancer patients and survivors. This includes my husband Tom, and children David and Rebecca. They were hearing dinner table conversations about cancer survivors in the early 1980s and must have thought I was nuts. But my colleague Anne Coscarelli (coauthor of the chapter on Psychosocial Care for Survivors) and I plugged away developing tools to measure the impact of cancer and its treatments on patients' lives, focusing on the development of rehabilitation interventions for cancer patients and survivors, and trying to persuade the funding agencies that there was merit in our cause. Now after more than 25 years, it is great to be acknowledged for my work and being able to provide leadership in this important aspect of cancer care.

I also want to thank my parents for providing me with the practical and financial support to pursue a career in medicine. Completing college in the late 1960s, with growing awareness of politics and social injustice, as well as being one of only three women in my medical school class, gave me a pioneering and individualistic spirit as I pursued medicine and postgraduate training. I knew I had to work hard to keep up with the guys, but also knew I was a lot smarter than most of them. So taking the time to look at the whole patient and figure out what was going on was a real challenge. Although this was often considered "soft" and "touchy-feely," my early work in quality of life assessment was the prelude to what ultimately became my focus on understanding and treating the late effects of cancer and its treatment. To my current research colleagues and collaborators – Julie Bower, Annette Stanton, Julia Rowland, Steve Cole, Michael Irwin, Tom Belin, and Steve Castellon – I am most grateful to you all for teaching me about the fields of psychology, psychiatry, biostatistics, psychoneuroimmunology, and neuropsychology, as I try to learn your disciplines and apply them to the problems of cancer survivors. Understanding the biology of cancer's late effects is now my passion, and devising targeted interventions (whether behavioral or pharmacologic) to address these late effects will hopefully be realized before I end my career.

This book must also be dedicated to my friends and colleagues who served on the IOM committee with me to write the 2005 report on cancer survivors – *From Cancer Patient to Cancer Survivor: Lost in Transition* – which is extensively cited throughout this book. Special thanks to Maria Hewitt, Ellen Stovall, Craig Earle, John Ayanian, and Betty Ferrell, who have all continued to work so hard to disseminate the messages in that report. We were full of excitement then about the results of our committee deliberations. But we were naive to think that our recommendations would be rapidly adopted – especially recommendation 2 regarding the treatment summary and survivorship care plan.

We are all looking forward to the time when there will no longer be a need for specialized cancer survivorship programs, and that such care will be a routine component of oncology care. To this end, this book works hard to rationalize the need for survivorship care as an essential part of high-quality medical care.

Patricia A. Ganz, M.D.

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Part I
Quality of Health Care for Cancer Survivors

Chapter 1
Specific Challenges in Optimizing Health Care for Cancer Survivors

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Introduction

In this chapter, we briefly describe the epidemiological and clinical factors that have led to the growing interest in cancer survivorship. We then describe the development of the term "cancer survivor", reviewing definitions that have been applied to the term. Finally, we highlight the challenges that cancer survivorship poses to both patients and the health care systems.

Epidemiological and Clinical Factors

It is estimated that over 40% of individuals born today will receive a diagnosis of cancer within their lifetime [1]. Worldwide over 10 million new cases of cancer are diagnosed every year, and this number will continue to rise due mainly to increase in size and aging of the population as well as early detection methods [2]. The burden and challenges that cancer poses to health care systems as well as on patients, their families, friends, and communities represent a global public health crisis that demands the attention of many. Fortunately, despite the increasing incidence of cancer, mortality rates have dropped significantly over the past three decades among the most prevalent cancer types (e.g., breast, colon, prostate) due to improvements in prevention, such as reduced tobacco use, screening and early detection, and the development of new, more effective treatments for some cancers. On average, two-thirds of cancer patients can now expect long-term survival [3].

There are now well over 12 million individuals living with a personal history of cancer in the USA and more than 25 million worldwide representing a tripling of the number of survivors since the early 1970s [1, 4]. In the next year, the first members

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of the baby boom cohort (those born between 1946 and 1964) will turn 65 and over the next 20 years the percentage of persons aged 65 years and older will nearly double in the USA to 20% of the population [5]. This, together with continued advancements in cancer survival rates, is expected to result in a doubling of the number of individuals living with a personal history of cancer by 2050 [6, 7].

Who Is a Cancer Survivor?

It was not long ago that cancer was considered an incurable disease. At that time, the term "cancer survivor" was used to describe the family members after the death of a loved one to cancer [8]. However, in 1985 an article entitled "Seasons of Survival: Reflections of a Physician with Cancer" appeared in the *New England Journal of Medicine* written by a young pediatrician named Fitzhugh Mullan, who had recently been treated for cancer [9]. In this article, Dr. Mullan reflected on his experience as a cancer patient and on his discussions with other cancer patients and was the first to propose the term "cancer survivor" in relation to the patient experience. In this now celebrated article, Mullan proposed three phases or "seasons" of survival including: (1) *acute survival*, which begins at diagnosis and covers the treatment phase; (2) *extended survival*, which is the period when the patient first finishes treatment and enters into a phase of watchful waiting; and (3) *permanent survival*, which is analogous to being "cured" and a time in which focus turns to long-term physical, psychological, and social effects of cancer treatment [9].

Since that time there has been some debate and much confusion about who a "cancer survivor" is with both broad and narrow definitions being proposed [10, 11]. The broad definition of cancer survivor is most commonly used and encompasses all individuals from the point of cancer diagnoses through the balance of their life including those who are actively dying from the disease and has also been expanded to include family and friends. This definition, or variants of it, has been adopted by numerous organizations including the National Coalition for Cancer Survivors (NCCS), the National Cancer Institute (NCI) Office of Cancer Survivorship, the Centers for Disease Control and Prevention (CDC), the American Cancer Society (ACS), and the Lance Armstrong Foundation (LAF) [8, 9, 12–17].

While an evidence-based definition of cancer survivor has yet to come forward, the period postacute diagnosis and primary treatments (may include recurrence of cancer) has emerged as a distinct phase in the cancer trajectory with its own set of unique and multifaceted challenges, and as such, many have chosen to focus on this specific time period arguing that this phase is distinct and remains poorly understood [18–20]. For example, while the NCI Office of Cancer Survivorship adopted the very broad definition of the survivor from the point of diagnosis, they have chosen to focus their research efforts on those individuals in the posttreatment phase [15]. For the purpose of this chapter, we will be using the narrower definition of cancer survivor and focusing primarily on the issues in the posttreatment phase.

Challenges Facing Cancer Survivors and Health Systems

Over the last decade, a number of advocacy groups including the NCCS, LAF, and ACS along with expert consensus panels and governmental reports [14, 19, 21] have contributed to an increased awareness of cancer survivorship and have strongly advocated for the need to address the unique medical, psychosocial, and economic challenges that cancer survivors face. Further, they have recommended improvement in the quality of survivorship care to address the unmet needs of cancer survivors, particularly their need for support as they transition from treatment to the follow-up phase of the cancer trajectory [19, 22, 23]. In 2006, a pivotal report entitled *From Cancer Patient to Cancer Survivors: Lost in Transition* very clearly identified survivorship as a distinct phase in the cancer trajectory [19]. The report included very clear consensus-based recommendations in terms of the essential components of survivorship care (see Table 1.1) [19] and outlined ten practical recommendations to improve the care provided to survivors many of which will require coordinated efforts and changes to our health care systems (see Table 1.2).

While the growing numbers of cancer survivors is without doubt a great achievement, the long-term impact of cancer and its treatments on the lives of patients and their families poses emergent and complex problems including: (1) lack of an evidence base to guide the identification, prevention, and treatment of persistent and long-term adverse effects of cancer and cancer treatments; (2) limited cancer health care resources, which are directed primarily toward treatment of new and advanced cancers; (3) the reliance on acute, intermittent care delivery; and (4) limited understanding of how to integrate across health care sectors, cancer-related health care needs with other chronic conditions experienced by many cancer survivors.

Similar to active treatment, the survivorship phase of the cancer trajectory is associated with a number of supportive care needs within the physical, psychosocial, spiritual, informational and practical domains [24–26]. Patients transitioning from primary cancer treatment to follow-up care face a number of significant challenges in order to restore and sustain their health and overall well-being and, for this reason, it is important to recognize that survivors represent a vulnerable and high-risk population. Quality of care for cancer survivors must start with

Table 1.1 Essential components of survivorship care

1. Prevention of recurrence and new cancers, and of other late effects
2. Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects
3. Intervention for the consequences of cancer and its treatment, for example: medical problems such as lymphedema and sexual dysfunction; symptoms, including pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; and concerns related to employment, insurance, and disability and
4. Coordination between specialists and primary care providers to ensure that all of the survivors health needs are met

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Table 1.2 Ten recommendations from the IOM report (From Institute of Medicine and National Research Council [19])

1. Health care providers, patient advocates, and other stakeholders should work to 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 treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This “Survivorship Care Plan” should be written by the principal provider(s) that coordinated oncology treatment. This service should be reimbursed by third-party payers of health care
3. Health care providers should use systematically developed clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined, and new evidence-based guidelines should be developed through public and private sector efforts
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. CMS, NCI, AHRQ, VA, and other qualified 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 CDC, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care and promoting the implementation, evaluation, and refinement of existing state cancer control plans
7. NCI, professional associations, and voluntary organizations should expand and coordinate their 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 payers 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, CDC, AHRQ, CMS, VA, private voluntary organizations such as ACS, and private health insurers and plans 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

shifting from a disease-focused approach to a wellness-centered approach that provides coordinated, patient-centered, comprehensive care, which includes both surveillance for recurrence and detection and treatment of the late and long-term effects of cancer and its treatment. In addition, care should include increased surveillance for other noncancer health problems and health promotion in order to minimize dysfunction and/or disability and maximize well-being and overall quality of life [19, 27, 28].

Almost all major types of cancer treatment (i.e., surgery, radiotherapy, chemotherapy, endocrine therapy) can result in side effects that can impair well-being, physical, and psychosocial functioning and overall quality of life and may persist after treatment ends (long-term effects). In addition, new late effects may also